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## Main Research Project and Service Evaluation Project

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Volume 1

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# Main Research Project and Service Evaluation Project

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Main Research Project

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Guiding intervention: Identifying parental risk factors for children's preoperative anxiety.

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Supervised by: Dr Jenny Cropper, Dr Emma Godfrey and Dr Kate Le Maréchal

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## Abstract

Up to 65% of children who undergo surgery may experience high levels of preoperative anxiety (Dreger & Tremback, 2006). Preoperative anxiety, poor compliance during induction of anaesthesia, and other maladaptive preoperative behaviours have been shown to predict postoperative maladaptive behaviours (e.g. Stargatt, Davidson, Huang, Czarnecki, Gibson, Stewart, & Jansen, 2006). Research has illustrated that parent's anxiety about their child's operation is related to children's preoperative anxiety, yet the relationship remains unclear (Kain, Maclaren, Weinberg, Huszti, Anderson & Mayes 2009). With better understanding of parent-child factors associated with increased levels of children's preoperative anxiety, it is hoped that children 'at-risk' can be identified in advance. The study aimed to investigate the association between certain child, parental and in-hospital setting factors with children's preoperative anxiety. The study also investigated the association between child self report and parental proxy report of children's preoperative anxiety.

This study employed a cross-sectional correlational design in 90 children aged 3-12 years who underwent elective surgery at the Evelina London Children's Hospital, and their parents. It was designed to test for relationships between parent's anxiety, parental coping, parenting style and children's preoperative anxiety. Correlational analyses showed that parent proxy report of children's anxiety was significantly associated with observational measures of children's preoperative anxiety. A multiple linear regression model revealed that child's age, parent's state anxiety and parental coping style predicted higher levels of children's preoperative anxiety.

Overall the findings suggest that older children, high levels of parental preoperative anxiety and parents' emotion focussed coping are risk factors for children's preoperative anxiety. Assessment of these factors needs to be incorporated into routine preoperative clinics and for interventions to be appropriately tailored and targeted to those parent-child dyads 'at risk'. Theoretical and clinical implications are discussed as well as limitations and avenues for future research.

## 1 Introduction

The introduction will review current understanding of children's preoperative anxiety and its effects on post-surgical outcomes. It will then describe risk factors for children's preoperative anxiety and discuss the evidence. After this, parental influences on children's preoperative anxiety and their theoretical backgrounds will be examined. The limitations and future research directions will be highlighted. Prevention and intervention strategies to treat children's preoperative anxiety are briefly described. Finally, the aims and hypotheses of the current study are summarised.

### 1.1 Day case and minimal stay surgery in British children

Approximately half a million children and young people undergo anaesthesia and surgery each year in England and Wales (Mason, Shotton, Wilkinson, Gough, Alleway, Freeth & Mason 2012). There has been a considerable change in the delivery of surgical services for children in the UK over the past 20 years. Minimal stay elective surgery is increasing in all areas, with developments such as increased day surgery, more frequent day-of-surgery admission and the "enhanced recovery" programme (Department of Health, 2010).

This rapid growth in minimal stay surgery has arisen mainly as a result of new surgical techniques, such as laparoscopic and minimally invasive surgery, improved anaesthetic practice, need for cost savings and patient preference (Audit Commission 1990, 1992, Hodge 1994; Murphy, 1994; Jarrett, 1995, 1997).

The pioneering growth and subsequent expansion in minimal stay surgery and day surgery healthcare within the United Kingdom has been welcomed by the majority of patients as, crucially, it involves minimal disruption to lifestyle (Greenwood, 1993). However, many authors argue minimal stay surgery and day surgery has a major impact on the psychological needs of patients (e.g. Mitchell, 2012). The extensive amount of time once associated with lengthy in-patient elective surgical procedures has all but disappeared or dramatically reduced. Therefore the opportunity for nurses to interact with patients, allay possible anxiety and provide information on the day of

surgery can be greatly reduced (Jlala, French, Foxall, Hardman & Bedford, 2010). Additionally, a considerable amount of recovery now occurs away from the hospital and professional staff. As surgery changes nurse's roles are changing and parents may have to assume greater responsibility in the care of their children during the perioperative experience (Justus, Wyles, Wilson, Rode, Walther & Lim-Sulit, 2006).

As the delivery of surgery to children continues to change, both numerically and in its surgical complexity, the hospital experience for children and their families is likely to have changed also. Although risk factors for children's preoperative anxiety have been documented for many decades and preoperative psychological preparation has been recommended, interventions remain underutilised and many have remained unchanged during the considerable rise and expansion in day surgery (Justus, 2006). Factors that investigators have identified as putting children at particular risk for preoperative anxiety are outdated.

To accommodate the changing face of surgery and shift of care practices need to adapt to meet the needs of children. Helping all day surgery patients manage their anxiety more effectively in the 21st century is a very realistic and attainable goal. The development of a more up-to-date understanding of the risk factors for children's preoperative anxiety is crucial for the comprehensive management of patients and the future success of day surgery. The most effective form of preoperative psychological management within minimal stay surgery and day surgery will therefore remain a challenge until a current understanding of the risk factors for children's anxiety can be identified.

## **1.2 Typical perioperative procedure in UK hospitals**

There are four phases of the surgical experience: preoperative, intraoperative, postoperative and perioperative. Each phase begins and ends at a particular point in the sequence of events that constitutes the surgical experience (American Society of PeriAnesthesia Nurses, 2000). The preoperative phase is defined as the period of time from when the decision for surgical intervention is made to when the patient is

transferred to the operating room table. The intraoperative phase is defined as the period of time from when the patient is transferred to the operating room table to when he or she is admitted to the postanesthesia care unit (PACU). The postoperative phase: period of time that begins with the admission of the patient to the PACU and ends after a follow-up evaluation in the clinical setting or home (American Society of PeriAnesthesia Nurses, 2000). The perioperative phase is defined as the period of time that constitutes the surgical experience; includes the preoperative, intraoperative, and postoperative phases of nursing care.

The process of the perioperative procedure outlined here is based on the UK guidelines and standards as set out by The Royal College of Anaesthetists (RCOA) (2013), Department of Health (DoH) (2003) and the Royal College of nursing (RCN) (2013).

Parents are encouraged to discuss with their children that they are going to be coming into hospital for a procedure and to give information as to how long this will be for and what is likely to happen (RCOA, 2013). It is recommended that all children attend a pre-assessment clinic to have an appropriate clinical assessment and the timely provision of information regarding the conduct of anaesthesia and pain relief (RCOA, 2013). Parents and children should be provided with good quality preoperative information which includes fasting guidelines and what to do if the child becomes unwell before the operation date (RCOA, 2013). All patients should be assessed before their operations by an anaesthetist. Parents and carers, as well as the child, should be given the opportunity to ask questions. Children are asked not to eat or drink (except water) for several hours (approximately six for solids and two hours for water) before the procedure.

When the child arrives at the hospital to the preoperative area depends on when their procedure is scheduled to take place. Some hospitals may have a number of operating theatre lists (e.g. morning, afternoon and all day sessions). The preoperative holding area of the past was a waiting area for patients before surgery. Today it has evolved

into a specialty area that is staffed by nurses and health care assistants who provide nursing assessment, monitoring, teaching, and emotional support to patients in a fast-paced environment (Sullivan, 2000). A play specialist should be available to provide preparation and support to the child or young person (DH, 2003; RCSENG, 2013).

Consent for the procedure should be obtained from the person with parental responsibility and in most cases from the children or young people themselves, in accordance with guidance from the Nursing and Midwifery Council and the General Medical Council (Nursing and Midwifery Council (2013).

Sedative pre-medication (a 'pre-med') is not routinely offered to children and young people before day surgery as the effects are unpredictable and can cause excessive drowsiness post-operatively (RCOA, 2013). The decision to give a pre-med is usually made by the anaesthetist, taking account of the child's or their parent's wishes. For those children receiving the anaesthetic intravenously, the use of a topical local anaesthetic cream such as EMLA or Ametop is recommended. This is applied onto the area where the cannula will be inserted to reduce the sensation of pain (RCOA, 2013). Some children have a cannula inserted on the ward, for others this does not happen until the child is in the anaesthesia room. The cannula allows the anaesthetist to give the anaesthetic in addition to any other necessary medicines.

The child is then usually accompanied from the ward to the operating theatres by one or both of their parents and a nurse from the child's ward. Some children prefer a gas induction of anaesthesia and others prefer an injection, i.e. a cannula. Anaesthetists usually prefer to give the anaesthetic through the cannula when possible (RCOA, 2013). Having talked about the benefits, risks and personal preferences, parents and carers (and in most cases the child or young person themselves) should be able to decide together the best method for induction (RCOA, 2013).

Parents are encouraged to stay with their child until they have been anaesthetised. After surgery most children are taken to a recovery room. Parents and carers must be reunited with their child as soon as is safe and the child is maintaining their own

airway (RCN, 2013). They should be invited to sit with the child in the recovery area and accompany the ward nurse on the journey back to the ward. Children and young people should be returned to the ward as soon as it is clinically appropriate to do so. Most children who have their investigations or operations carried out as 'day stay' patients, go home on the same day. Depending on the type of surgery and local criteria, children and young people should be offered fluids and a light diet as soon as possible on return to the ward (RCN, 2013). A set of clear discharge criteria for home must be in place which should encompass the pain relief at home following day surgery (RCOA, 2013).

### **1.3 Children's preoperative anxiety**

Hospitalisation and surgery are thought to be some of the most difficult experiences that children and their parents have to face. It has long been recognised that undergoing surgery can be a very anxiety provoking experience for children. In fact, this phenomenon has grasped the interest of clinical researchers for more than 70 years. For example, Pearson (1941) observed significant emotional reactions in young children undergoing anaesthesia and surgery. It has since been suggested that between 40% and 65% of children who undergo surgery may experience extreme preoperative anxiety (e.g. Wollin, Plummer, Owen, Hawkins, & Materazzo, 2003; Dreger & Trembeck, 2006).

Preoperative anxiety<sup>1</sup> refers to anxiety regarding impending surgical experience (Wright, Stewart, Finley & Buffett-Jerrott, 2007). Anxiety can be viewed as having three specific components: physiological, behavioural and cognitive (Kendall, Chansky, Freidman, Kim, Kortlander & Sessa, 1991). The behavioural aspects are the most obvious to an observer, for example, avoidance (trying to escape medical personnel), rigid posture, trembling, crying or other verbalisations (Burton, 1984; Wright et al., 2007). The second component of the anxiety response - cognitions - can be conceptualised as being a precursor to the behavioural response and have been described as 'pre-surgical worries' (Mendez, Quiles & Hidalgo, 2001). Authors have suggested that a child's 'pre-surgical worries' are related to their concerns about anaesthesia and surgery including fear of separation, fear of physical harm, fear of the unknown, fear of death, fear of losing control and uncertainty of the limits of acceptable behaviour (Kain, Caldwell-Andrews, Weinberg, Mayes & Wang, 2005) as well as uncertainty about needles and unfamiliar people (Wollin et al, 2004). Several studies have described the physical components of preoperative anxiety such as heart palpitations, tremors, dizziness, nausea and fatigue (Lazarus, 1991). Significant correlations between heart rate, blood pressure, and behavioural ratings of anxiety have also been reported (Kain, Mayes, Wang, Caramico, Krivutza, & Hofstadte, 2000). In this study, it is the behavioural and the cognitive components that are of interest. It is not within the scope of the study to measure physiological responses.

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<sup>1</sup> Although the terms 'fear' and 'anxiety' are often used interchangeably both in literature and in practice, there is a difference between them. Fear is a negative emotion that is thought to arise as an alarm to a dangerous and/or life threatening situation (Albano et al., 2000); anxiety is defined as a nonspecific feeling of apprehension towards a concrete situation that does not necessarily require previous experience, and is not proportional to the response that is triggered in the individual (Alwin et al., 1991; Milgrom et al., 1995; Rayen et al., 2006). In the literature on anxiety and childhood anxiety disorders, fears are generally considered to be an immediate defensive reaction to threatening stimuli, whereas anxiety is defined as being a more diffused response with apprehension about some future event (Beidel and Turner, 2005; Johnson and Melamed, 1979). A phobia, on the other hand, is defined as being an excessive fear that is characterised as being out of proportion to the demands of the situation, it cannot be explained or reasoned away and is beyond voluntary control and leads to avoidance of the feared situation (Marks, 1969). For the purposes of this account, the term anxiety will be used to denote the experience of fear, anxiety, distress and phobia.



In many cases, the period of a child's hospitalisation and surgery requiring general anaesthesia is full of anxiety and there is great variation in the way a child expresses and manages their hospital anxiety (Woodgate & Kristjanson, 1995; Woodgate et al., 2003). This study is concerned with those risk factors involved in the experience of high levels of preoperative anxiety.

#### **1.4 Consequences of preoperative anxiety**

There is a growing body of research that shows increased anxiety in children before surgery predicts adverse postoperative outcomes, such as increased incidence of emergence delirium<sup>2</sup> (Kain, Caldwell-Andrews, Krivutza, Weinberg & Gaal, 2004), increased pain (Wallace, 1986 and Johnston, 1986) and increase in the incidence of maladaptive postoperative behaviours (e.g Kain, Caldwell-Andrews, Mayes, Weinberg, & Wang 2007; Stargatt et al., 2006). These behavioural changes have been a target of interest for more than 70 years. Eckenhoff (1953) in a retrospective study of more than 600 children identified a link between preoperative child anxiety and postoperative negative personality changes. This led to the recognition of the importance of addressing children's anxiety in the preoperative period. Negative behavioural changes observed post-operatively include general anxiety, night-time crying, enuresis, separation anxiety, eating disturbances, sleep-related problems, temper tantrums and parent-child conflict and negativity (Squires et al., 1995; Kain, Mayes, Thereasa, O'Connor, Domenic & Cicchetti, 1996; Kain, Mayes, Wang, Caramico & Hofstadter, 1998; Wollin et al., 2004) and have been described in as many as 50-60% of children undergoing surgery (Kain et al., 2004; Kain, Mayes, Caldwell-Andrews, Karas & McClain, 2006). Children who exhibit more anxiety preoperatively may be three times more likely to exhibit such negative behaviours (Litke, Pikulska & Wegner, 2012).

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<sup>2</sup> Sikich N, Lerman (2004) defines emergence delirium as "a disturbance in a child's awareness of and attention to his/her environment with disorientation and perceptual alterations, including hypersensitivity to stimuli and hyperactive motor behaviour in the immediate post-anaesthesia period."

Although studies have shown the frequency of these behaviours to decrease rapidly over time (Kain, Mayes, Wang & Hofstadter 1999), Kain et al., (1996) found that 67% of children had new negative behaviours on the first day after surgery, 45% on day two, and 23% at two weeks after surgery. These changes could persist for up to up to 6 months in 20% of children and for up to one year in 7.3% of children (Kain et al., 1996).

Yet, despite these findings on anxiety, it is not often assessed and is therefore subsequently undertreated (Crandall, Lammers, Senders, Savedra, & Braun, 2007). An understanding of the effects that a child's level of preoperative anxiety has on postsurgical outcomes drives the need to direct efforts to reduce preoperative anxiety for these children (Wright et al., 2007). Thus, researchers have sought to identify children who are at a particularly high risk for developing high levels of anxiety before surgery to help guide preoperative preparations (Ahmed, Farrell, Parrish & Karla 2011).

### **1.5 Measures of children's preoperative anxiety**

There are a number of methods already employed to assess childhood anxiety in general, and specifically children's anxiety in a hospital setting. The measurement of children's anxiety can be achieved through the observation of behaviour, physiological measurement, and/or through self-report (Kendall, 1991). Within the context of the present study, two methods of anxiety assessment were of primary interest: child self-reported and observer-rated. Blount, Piira, Cohen and Cheng (2006) state that the choice of specific measures should be determined by children's developmental level, the nature of the setting and whether the assessment is for research or clinical purposes.

Typically researchers attempt to measure levels of preoperative anxiety at certain “stress points” during the preoperative phase. In the literature the main stress points identified are:

1. In the preoperative ‘holding area’
2. Separation to theatre
3. In the induction room
4. During induction.

Earlier research examined preoperative anxiety upon children’s ‘separation’ from their parents to theatre. Current good practice guidelines in the UK recognise the value for parents to remain with their child and accompany them from the ward to the operating theatres. Thus it was decided that this no longer an important ‘stress point’ to measure and is not a focus of this study.

The majority of studies examine children’s preoperative anxiety in the preoperative ‘holding area’ (e.g. Kain et al., 1996; Brophy & Erikson, 1990; Wollin et al., 2003). The preoperative ‘holding area’ refers to a ward or area where patients wait for up to a 2-3 hours before their surgery where the preoperative preparation takes place.

In the induction room and during induction are periods which researchers have typically measured preoperative anxiety to examine its impact on difficulty of induction, and/or related anaesthetic concerns.

This study is concerned with identifying risk factors for children’s preoperative anxiety. In line with previous literature and upon Kain et al.’s (2000) recommendations, it was decided that children’s anxiety levels should be assessed in the preoperative holding area. Further, it was deemed unnecessary to measure anxiety levels at induction, which could place undue burden on children and their parents during the most stressful procedure the child experiences when undergoing surgery (Kain et al., 2000; Lumley, Melamed & Abeles, 1993).

Assessment of children's preoperative anxiety in this study refers to the anxiety levels as assessed in the 'holding area' (also referred to as the 'waiting area' or 'preoperative ward') in the period before being taken to the operating room or theatre. Unless otherwise stated the studies referred to in this introduction also refer to preoperative anxiety as assessed in the holding area.

### **Self-report**

There is no clear consensus on the best approach to obtaining self-report from children (Chambers & Johnston, 2002). However, simplified wording/instructions, concrete response options, and an option for the rater to respond nonverbally are important developmental considerations (Sattler, 2002). Several multi-item self-report measures of anxiety are available e.g. The Children's Fear Survey Schedule-Revised (Barrios, Replogel & Anderson-Tisdelle 1983); The Children's Manifest Anxiety Scale-Revised (Reynolds & Richmond 1978); The Fear Survey Schedule for Children-Revised (Ollendick, 1983); The State Trait Anxiety Inventory for Children (Spielberger, 1973). However, there are a number of limitations to employing a self-report questionnaire for the assessment of anxiety, particularly in the preoperative setting. First, the child must have acquired a particular reading level in order to complete the measure, which therefore excludes young children or those with English as a second language, or non-English speakers. It is also a challenge to obtain a self-report if the child has a cognitive or communicative difficulty (Breau & Burkitt, 2009). Second, self-report questionnaires typically take more time to complete than is available preoperatively.

As a result, the existing self-report measures for children's preoperative anxiety have relied on various types of visual analogue scales, numerical rating scales, and pictorial 'FACES' scales, which may have advantage by virtue of simplicity (Crandall et al., 2007). Pairing a picture with a child's inner state has been suggested as a useful assessment technique (Sattler, 2002). McMurtry, Noel, Chambers & McGrath (2011) developed the Children's Fear Scale (CFS; based on the adult Faces Anxiety Scale (McKinley, Coote & Stein-Parbury, 2003) with young school-age children to measure anxiety during venepuncture. The one-item scale consists of a row of five sex-neutral faces ranging

from a no fear (neutral) face on the far left to a face showing extreme fear on the far right. The rater responds by indicating which of the five faces matches his or her level of anxiety. McMurtry et al., (2011) argue that faces scales are easier for children to interpret because they do not require them to translate their inner experience to a number. As a result, faces scales are frequently used as self-report measures of children's preoperative anxiety (Champion et al., 1998; Kuttner and LePage, 1989). However, FACES scales have been criticised because they only assess a single item, which is vulnerable if the child does not specifically understand the item (Nillson Buchholz & Thunberg, 2012). Despite the methodological challenges of administering self-reports, it is still considered the golden standard (Huguet, Stinson & McGrath., 2010).

### **Observational**

Among the first of the observational measures was the Procedural Behaviour Rating Scale (PBRs) (Katz, Kellerman & Siegel, 1980). With the PBRs, the occurrence or non-occurrence of 11 behaviours thought to be indicative of behavioural distress were recorded during the 'anticipatory', 'encounter', and 'recovery' phases of medical procedures.

Based in part on the PBRs, Jay, Ozolins, Elliott and Caldwell (1983) developed the Observational Scale of Behavioural Distress (OSBD). With the OSBD, 11 distress behaviours are coded as occurring or not occurring over 15- second intervals. Individual distress behaviours are weighted on a scale from 1.0 to 4.0 on the basis of the severity of distress they represented. Weighted scores are added to provide phase or whole session distress scores.

The 'Child-Adult Medical Procedure Interaction Scale' (CAMPIS: Blount, Corbin, Sturges, Wolfe, Prater, & Denise James 1989) and the CAMPIS-R are scales that were specifically designed to assess adult and child verbal behaviour during medical procedures (Blount et al., 1989, 1990 and 1997). Although providing a wealth of information, they are limited in that the use of it may take many hours of coding per

child. Furthermore, the CAMPIS and the CAMPIS-R were developed to assess children undergoing 'painful' procedures. As such, the scale has not been validated with hospitalised children undergoing procedures under general anaesthetic.

Over the last decade, the modified-Yale Preoperative Anxiety Scale (m-YPAS) (Kain Mayes, Cicchetti, Bagnall & Finley, 1997) is an observational measure that has become the measurement tool of choice for assessing preoperative anxiety. This scale has 'good'-to-'excellent' reliability and validity for measuring children's anxiety in the preoperative holding area and during induction of anaesthesia (Kain et al., 1997). This scale determines a child's level of anxiety by evaluating a series of behaviours from calm to severe and is appropriate to use preoperatively.

Some of the drawbacks associated with the use of psychological instruments that have been specifically designed to assess preoperative anxiety is that they may be time-consuming, require training and often necessitate videotaping so that behaviours might be coded, or perhaps even transcribed and coded at a later time (Kain et al., 2006). In reality practitioners must rely on their own perception of the child's anxiety when assessing the child preoperatively (Kain et al., 2000). Therefore, efforts have been directed to assessing parents or close carer's ability to accurately predict children's preoperative anxiety levels instead (Maclaren, Thompson, Weinberg, Fortier, Morrison, Perret, & Kain, 2009).

Franck and Callery (2004) argue that parent or close carer participation is essential when carrying out the assessment of the child, as they can contribute valuable information on normal behaviour and any deviation due to illness. Limited research has been conducted to investigate whether a child's self-report of anxiety agrees with that of the parent or carer. One study by Maclaren et al., (2009) assessed the ability of mothers to predict the anxiety of children during induction of anaesthesia. A total of 125 children aged 2 to 16 years, their mothers, and anaesthesiologists were studied. They found that mother predictions (using the VAS-anxiety) were not significantly related to children's anxiety (using the m-YPAS) during induction.

McMurtry et al., (2011) filmed 100 children ages 5-10 years and their parents were during venepuncture. Parents provided a proxy rating of their child's fear using the CFS immediately after the procedure. A moderate correlation was found between parents' and children's ratings of child fear on the CFS. Bringuier, Dadure, Raux, Dubois, Picot and Capdevila (2009) examined 100 children scheduled for elective surgery and general anaesthesia. A child's self-report and parent proxy reports of children's preoperative anxiety were evaluated using the VAS. They found a significant correlation between children's self-report and parent proxy report. Nevertheless, the proxy report was significantly higher when the parents were anxious (Bringuier et al., 2009).

Cohen et al., (2004) suggest that such conflicting results are likely to reflect these overall methodological approaches (e.g. self-report, observational measures) discriminate between different *constructs* of anxiety rather than expressing a true incongruence. McGrath et al.'s (2008) recommendations stress the importance of including multiple outcome domains in relation to the measuring of anxiety during invasive medical procedures in paediatric patients. Further research is needed to better explain discrepancies between parent and children's assessment of preoperative anxiety.

In this study examiner observational measure of children's preoperative anxiety will be chosen as the primary outcome measure, since observed anxiety can be assessed by a standardised measure that is valid for all children regardless of age or developmental level. Given the limited literature examining parents' ability to accurately assess children's preoperative anxiety and based on the recommendations from Stinson et al., (2006) and Cohen, Blount, Cohen and Johnson (2004), self-report and parent reports of children's preoperative anxiety will also be measured and their associations will be explored.

## **1.6 Section summary**

For a number of years it has been known that admission to hospital, especially for surgical intervention, can cause considerable anxiety (for a review see Wright et al., 2007). Preoperative anxiety can produce in children physiological, emotional, cognitive, behavioural, and interpersonal changes (LeRoy, Elixson, O'Brien, Tong, Turpin, & Uzark 2003). The causes of preoperative anxiety have been well documented for many decades and much care has been recommended although unfortunately it is not systematically assessed nor implemented.

## **1.7 Identifying children at risk**

Brewer, Gleditsch, Syblik, Tietjens and Vacik (2006) explained how the stressful events of admission to hospital for surgery, i.e. separation from family, fear of the unknown, loss of control and fear of pain contribute to a child's anxiety both before and after hospital and the child's cognitive appraisal of the event determines coping behaviours. Variables that have been found to influence preoperative anxiety in children, include their age, gender, previous hospital experience, surgery type, parental anxiety, and child temperament (for a review see Ahmed et al., 2011).

In the following section the literature for each of these factors and their theoretical backgrounds will be examined and evidence for their effects on children's preoperative anxiety will be discussed.

## **1.8 Child's age**

Research appears to show mixed results for the effect of age on children's preoperative anxiety. A number of studies found that younger age is associated with higher levels of children's preoperative anxiety (Kain et al. 2000 and Kain et al. 2006). Caldwell-Andrews, Blount, Mayes & Kain (2005) examined 289 children aged 2–12 years undergoing outpatient, elective surgery and general anaesthesia. Children's preoperative anxiety was assessed (using the m-YPAS) and they found younger (aged 2–6.9 years) children were more anxious when compared with older children (aged 7–12 years). Kim et al., (2012) investigated predictive factors for the requirement of



preoperative sedation in 455 patients aged 2 – 12 years scheduled for surgery requiring general anaesthesia. The authors found that younger age (< 6 years old) was one of the predictors for requirement for sedative premedication.

In contrast, Kain et al.,’s (1996) study looking at predictors for children’s preoperative anxiety found that older children (aged 7 years and above) demonstrated higher levels of anxiety in the preoperative holding area (Kain et al., 1996). Cagiran, Sergin and Deniz (2014) and Wright et al., (2013) found no association between children’s age and their level of preoperative anxiety. These contradictory results may be explained by methodological issues such as small sample sizes and inappropriate measurement tools for anxiety. Kain et al., (2006) study only included 56 children in the analyses and therefore it is likely that this small sample size resulted in inadequate power. Cagiran et al., (2014) study used the Venham Picture Test (VPT) to measure children’s preoperative anxiety. The VPT is a self-report measure that comprises of eight cards with two figures on each card. Eight pairs of pictures depicted cartoon boys in contrasting moods (one anxious figure and one non-anxious figure); children are asked to choose the picture from each card that they most feel like at that time. There is no published information about the reliability and validity of the scale (Buchanan & Niven, 2002). The VPT has also been criticised because the figures on the cards are all male, which may present problems when the young patient is a girl. In addition, some of the figures are ambiguous in what they are portraying (Finley & others (2002).

According to Piaget, children’s anxiety manifests differently according to their cognitive development. Piaget’s perspective suggests that children’s ability to think and reason progresses through a series of stages. He divided cognitive development into four stages; the sensorimotor stage (0-2 years old), the preoperational stage (3-6 years old) and the concrete operational stage (7-11 years old) and the formal operational (11-15 years old) (Piaget, 1963). Children, aged between 3 and 6 years, in the preoperational stage of development focus on magical thinking and are less able to distinguish reality from fantasy. As children get older and enter into the concrete operational stage, their cognitive abilities mature and normally they become able to

think rationally through 'step by step' processes (Gedaly-Duff, 1991). The theory states that children are able to rationally think through the surgery process step by step. This logical progression may enable children to develop coping behaviours to help deal with the stress of surgery, thereby reducing anxiety.

Today, the literature shows that children's development is more complex and it is also related to social and cultural factors and earlier experiences (Doverborg & Pramling-Samuelsson, 2003; Sommer, 2005). For example, a group of researchers, who are known as neo-Piagetian theorists, advanced models that integrate concepts from Piaget's theory with concepts from cognitive and differential psychology (e.g. Demetriou, 1998). The neo-piagetarian showed that the successive levels or stages of cognitive development are associated with increasing processing efficiency and working memory capacity. These increases explain differences between stages, progression to higher stages, and individual differences of children who are the same-age and of the same grade-level (e.g. Morra, Gobbo, Marini et al., 2007). Childhood is thus a period of intensive changes that are explained by theories on cognitive development, thinking and language (Morris et al., 2009), psychosocial development (Morris et al., (2009), development of holistic understanding of inner and outer experiences through play and fantasies (Woodhead, 2002), parent-child relationships (Zang & Chen, 2010) and development of 'self-narrative' (Conway & Pleydell-Pearce 2000). Although most theories on children's development agree that age is of importance in how children understand their existence, more recent theories are less inclined to adopt strict categorisations in respect of age.

Kain et al., (2001) suggest that for younger children (1-6 years), the greatest anxiety during the perioperative period is likely imposed by being separated from their parents and by meeting strangers whose faces are often concealed by masks. Bibace and Walsh (1980) assert that young children may be co-operative but have little understanding of procedures, instead focusing on what happens outside their body. In addition, authors have suggested that younger children (under 6 years) may not have the cognitive and coping abilities to handle the preoperative period successfully, given

that they are generally more dependent on adults' comforting interventions in stressful situations (Cuthbert & Melamed, 1982; Hyson, 1983; Melamed & Ridley-johnson, 1988). Although the younger child does not necessarily have the cognitive capacity to anticipate potential dangers that are beyond separation, the older child (over 6 years) may anticipate pain and fear 'going to sleep.' Coyne (2006) states that older children have more physical awareness and may worry about the effects of surgery on their body. They may rely on a number of coping strategies, including verbal questioning and cognitive mastery (e.g. learning about heart monitors or about what surgeons do), to manage their anxiety (Coyne, 2006). Kain, Wang, Mayes, Krivutza & Teague (2001) argues that the needs and fears of children are very much a function of social adaptability and cognitive development in this situation. Overall, previous studies highlight the importance of children's age on levels of preoperative anxiety and provide provisional evidence to support that children of different ages need to be prepared based on their developmental level.

### **1.9 Child's Gender**

It has been suggested that gender is linked to levels of children's preoperative anxiety. Mendez et al., (2001) found increased anxiety in girls, whereas Caladas, Pais-Ribeiro & Carneiro (2004) obtained an effect of increased anxiety in boys. A study of 1250 children aged between 3 and 12 years demonstrated that a child's gender had no effect on preoperative anxiety levels during induction of anaesthesia (Davidson, Shrivastava, Jansen, Tanatti, Emiroglu & Alper 2006), which was consistent with the findings from Cagiran et al., (2014). However a number of studies have found no effect of child gender on children's preoperative anxiety (Kain et al., 2000; Wollin et al., 2004). The relationship between child's gender and the level of preoperative anxiety remains unclear.

### **1.10 Child's temperament**

Because surgery is an important, novel situation faced by substantial numbers of children, researchers have focused on whether temperament can predict the anxiety experienced by children preoperatively. For example, previous work has shown that

shy, inhibited children displayed higher levels of child-rated anxiety in the preoperative period (Kain et al., 1996). Further, impulsive children were at an increased risk of the development of general and separation anxiety postoperatively (Kain et al., 1996). More recently Finley et al., (2006) examined temperamental predictors of anxiety at anaesthetic induction. In their study, children were randomly assigned to receive either midazolam (a benzodiazepine with anxiolytic and sedative properties) or a placebo. Baseline levels of impulsivity were associated with adverse reactions (i.e. greater anxiety) at anaesthesia induction in the midazolam-treated group, but not in children treated with a placebo. These results suggest that high levels of impulsivity may contraindicate the use of midazolam as a preoperative sedative/anxiolytic medication in children.

Kain et al., (2000) examined the relationship between social adaptability, cognitive abilities, and other personality characteristics and preoperative anxiety in 60 children aged 3 to 10 years. They demonstrated that child with poor social adaptive capabilities (as measured by the Vineland Adaptive Behaviours Scales (Sparrow et al., 1984)) were more anxious. Temperament (sociability) was also found to be a significant predictor for higher levels of children's preoperative anxiety, which is in agreement with previous investigations that assessed predictors for the behaviour of the child in the preoperative setting (Melamed, 1988; Kain et al., 1996). Kagan, Reznick and Snidman (1978) reported that temperament characteristics can be used to predict how a child will respond emotionally in a stressful situation. For example, children who are 'shy' or 'inhibited' tend to become more anxious in novel settings as suggested by the adrenocortical response and elevated heart rate (Kagan et al., 1987).

### **1.11 Child's coping**

Only one study was identified that described children's coping strategies during admission to hospital for inpatient orthopaedic surgery and how it related to their behaviour at home once discharged. LaMontagne Hepworth and Salisbury (1997) found that children/adolescents that focused on the concrete-objective aspects of surgery (problem- focused) had significantly more positive activity outcomes after

discharge from hospital. Similar results were reported in studies of children with chronic medical illness. Eiser (1993) synthesized the results of a number of studies and reported that younger children were more likely to use problem-focused coping and children who favoured this coping strategy were better adjusted and accepting of the disease and tended to be more physically active.

In the literature on children's procedural pain, certain child coping behaviours (audible deep breathing, nonprocedural talk by the child and humour by the child) are thought to reduce child distress (Blount et al., 1989). Burstein and Meichenbaum (1979) found that low-defensive children, including those who showed a preference for medically related toys, exhibited significantly less anxiety following hospitalisation. Blount, Sturges and Powers (1991) carried out research with children undergoing bone marrow aspirations and lumbar punctures. They found that high-coping children were more likely to cope following adults' distraction and coaching than were the low-coping children. However, this study did not consider potential moderators of effects (e.g., pre-existing behavioural difficulties, type of procedure, and number of previous procedures under GA). No other studies identified from the literature on children's hospitalisation for surgery reported the coping strategies adopted by children. One reason for this is possibly due to the difficulty in measuring the process of coping especially in younger children who do not have the cognitive or linguistic skills to explain how they cope and the lack of standardised measures (Blount, Simons, Devine, Kjaaniste, Cohen, Chambers & Hayutin 2008). Older children with chronic illnesses have participated in studies of this nature and have either been asked to explain how they coped or to identify coping strategies from a list of possible strategies such as the KIDCOPE tool developed by Spirito, Stark and Tyc (1989), which has been developed for use in children 7 to 18 years (Eiser 1993).

Coping and stress exist within a complex framework, with the effectiveness of the particular coping strategies that are employed influencing subsequent adjustment outcomes (e.g., psychosocial, emotional, and behavioural functioning; quality of life;

and physical health), and potentially even leading to growth and greater well-being (Blount et al., 2008).

In addition to the lack of appropriate measures child coping, it is beyond the scope of this project to understand the dynamic interplay among stress and coping and therefore it was decided that children's coping will not be measured in this study.

### **1.12 Previous hospitalisations**

Several studies have examined the effects of previous hospitalisation and complicated medical encounters on children's anxiety responses (e.g. Lumley, Melamed, Abeles 1993). Jay et al., (1983) found a negative correlation between the number of previous medical experiences and children's anxiety during bone marrow aspirations, suggesting a habituation effect. Lumley et al., (1993) and Vetter (1993) reported that previous hospitalisation was a predictor for distressed behaviour post-operatively. Kain et al., (2006) found that children who underwent surgery previously were calmer during induction of anaesthesia. However, these children were also older and their parents were less anxious and therefore the impact of previous surgery on anxiety may be attributed to the variable of age and parental anxiety. Other studies have not found this link, (Katz et al., 1980; Brophy & Erickson 1990), or in fact have found the opposite; children without previous experience of surgical procedures had higher levels of preoperative anxiety (Mendez et al., 2001). Some authors suggest that previous hospital experiences play an important role in determining child and adolescent responses to invasive medical procedures, particularly when those experiences are perceived negatively (Dahlquist, Gil, Armstrong, DeLawyer, Greene & Wuori, 1986 and Kain et al., 1996). Wollin et al., (2003) and Kain et al., (1996) demonstrated that an increase in a child's anxiety was significantly related to a poorer quality of previous medical experiences. However, studies comparing quality of previous experience often lack statistical power as a result of the relatively small sample size (e.g. Bijttebier, Patricia, & Vertommen, 1998). Further studies are needed to investigate the effect of the quantity and quality of previous hospitalisations on children's preoperative anxiety.

### 1.13 Sociodemographic factors

Very few studies have examined the influence of any parent or family demographics on children's preoperative anxiety. Davidson et al., (2006) examined maternal sociodemographic characteristics and found no effect on children's anxiety levels during induction of anaesthesia. One study reported that the maternal education level had no impact on anxiety (Shevde and Panagopoulos, 1991), whereas another stated that the level of anxiety increased as the maternal education level increased (Power, Howard, Wade, & Franck 2012). In Cagiran et al.'s (2014) study maternal education level and family socio-economic status had no effect on the child's anxiety status. Kain et al., (2000) examined the relationship between sociodemographic factors and preoperative anxiety in 60 children aged 3 to 10 years. They found that Mother's age, child's ethnic origin, number of siblings and sibling order, marital status of parents, and parental social status were not significant predictors for children's preoperative anxiety. However, only 56 children were included in the analyses therefore the lack of significant findings may have been due to the small sample size and hence reduced power to detect an effect.

### 1.14 In-hospital setting factors

Wollin et al., (2003) examined 120 children aged 5-12 years scheduled for surgery requiring general anaesthesia. Factors associated with increased levels of anxiety (measured using the m-YPAS) in the children included increased number of people in the room at induction of anaesthesia and longer waiting time between admission at the hospital (Wollin et al., 2003). However they did not find any significant associations between how many people accompanied the child to hospital and children's preoperative anxiety and how long the child had known that he/she would be coming to hospital and children's preoperative anxiety. The type of procedure has been found to be a predictive factor for negative post-operative behavioural changes, with genitourinary surgical procedures being associated with the most changes and the insertion of grommets the least (Kain et al., 1999). Thompson et al., (2006) studied children aged 2-12 years undergoing elective outpatient surgery. Procedures were

categorised as either ‘major’ or ‘minor’ surgery by an attending anaesthesiologist. They found no differences in children’s preoperative anxiety based on procedure type. A meta-analysis conducted in 2003 found no link between type of procedure and the incidence of post-operative behavioural problems (Watson & Visram, 2003). It is uncertain whether there is a potential link with the reason for the surgery (i.e. whether it is for cosmetic or functional reasons) and preoperative anxiety.

### **1.15 Section summary**

In summary, studies investigating risk factors for children’s preoperative anxiety are sparse and show inconsistent findings. These contradictory results may be explained by methodological issues such as small sample sizes, inappropriate measurement tools for anxiety and lack of statistical methods for controlling confounding variables. To date, little attention has been paid to adult influences on children’s preoperative anxiety; hence this will be further explored, and is reviewed next.

### **1.16 Parental Risk factors**

Parental participation is integral to the preoperative preparation process, starting with parental agreement to a child’s involvement (Purcell, 1996). Ahmed et al., (2011) conducted a review of risk factors for children’s preoperative anxiety and concluded that addressing preoperative anxiety should be a multimodal effort. The authors suggested that families are an integral part of the perioperative care team and efforts should be made to establish collaborations by openly communicating, developing a shared vision for the care of the child, and building a cohesive care team that includes healthcare providers and family members throughout the perioperative period. They suggested that in order for this to become the standard of care, and before treatment outcome research can be carried out on family preparation programs, proper understanding of the child and parental risk factors for heightened preoperative anxiety need to be established. Although research provides support that children’s preoperative anxiety is related to parent’s anxiety, the relationship continues to remain unclear (Kain, 2009). As children are adept at perceiving parental cues (LeRoy et al., 2003), increased knowledge of parental factors related to children’s increased



preoperative anxiety might assist in identifying parents of 'at risk' children and target them for intervention.

### **1.17 Parent's preoperative anxiety**

A review of the literature reveals that parents also experience intense stress and feelings of helplessness when their children undergo surgery (Fielding & Tam, 1990; Brennan, 1994; Fielding, 1994; Kain, 1996; Cohen et al., 1997). There is also evidence to suggest that parents themselves show very high levels of preoperative anxiety (Lansdown & Sokel, 1993). Thompson, Irwin, Gunawardene and Chan (1996) interviewed 100 parents before their child's surgery and identified 47% of parents as highly anxious measured using the Leeds scale for self-assessment of anxiety. Shirley, Thompson, Kenward, and Johnston (1998) measured the anxiety levels in 100 parents of children scheduled for elective surgery and found that 42% of parents were significantly anxious. They found that the 'anxious' parents were specifically anxious about the surgery, anaesthesia, postoperative pain and treatment, and being in hospital (Shirley et al., 1998).

Ogilvie (1990) examined the experiences of parents at stressful points during their child's hospitalisation. Results of direct observations and interviews indicated that parents perceived many parts of the hospitalisation anxiety provoking and even reported higher anxiety than their child (Ogilvie, 1990). Frank and Spencer (2005) carried out a review that critically analysed the published research literature on providing information about children's anaesthesia to parents. Within their review they examined eight studies looking at parental anxiety related to children's general anaesthesia and found that only one study included psychometric evaluation of instruments to measure parental anxiety (Miller, Wysocki, Cassady, Cancel & Izenberg, 1999). The remaining studies used likert-type scales (Hatava, Olsson & Lagerkranser 2000), forced choice questions (Waisal & Troug, 1995 and Karl et al., 1990) and open-ended questions (Shirely, Thompson, Kenward & Johnston, 1998; Thompson et al., 1996) but did not report on psychometrics. In summary, Frank and Spencer (2005) assert that the five descriptive studies suggest that parents of children preparing for

surgery are extremely anxious and that anaesthesia is one of the most anxiety provoking factors of their children's surgery. However Frank and Spencer (2005) state that these findings must be interpreted with caution because the study samples and measures were diverse and only selective aspects of the experience were examined.

A number of studies have shown that parental anxiety predicts child anxiety and pain across a range of medical and nonmedical events (e.g. Lipani and Walker, 2006). Cagiran et al., (2014) showed high maternal anxiety was related to increased preoperative anxiety levels in children undergoing a surgical procedure. Other research has demonstrated that children of parents with high levels of anxiety are more fearful, nervous and worried, compared with children of parents who have low levels of anxiety (Dreger & Tremback, 2010; Davidson et al., 2006). Preoperative parental anxiety has been shown to lead to increased anxiety in children, not only during the surgical procedure but also in the postoperative period (Shirley et al., 1998; Kain et al., 1996). However, some studies have failed to find significant correlations between parent anxiety and child medical distress (Dahlquist et al., 1994; Frank et al., 1995).

Some authors have separated state and trait anxiety and found positive correlations between children's preoperative anxiety and parental trait anxiety and not state (e.g. Jacobsen et al., 1990). Kain (2006) examined child's compliance during induction of anaesthesia and found significant effect of parent's state and trait anxiety. A very recent study by Cagiran et al., (2014) investigated mother's anxiety relating to surgery and anaesthesia, fasting before surgery, postoperative treatment, and pain and hospitalisation of children aged 3–12 years who were scheduled for surgery. They found that the highest levels of parent's anxiety related to surgery and anaesthesia (Cagiran et al., 2014). In a similar study asking the same questions parental anxiety levels were heightened regarding surgery, anaesthesia, postoperative treatment and pain, and hospitalisation, whereas parents were not anxious about preoperative fasting (Thompson et al., 1996).

Research comparing the behaviour of clinically anxious versus non-anxious mothers suggests that mothers with high state anxiety are less emotionally sensitive and might communicate their anxiety to their children (e.g. Nicol-Harper et al., 2007; Woodruff-Borden, et al., 2002). Kain (1996) proposed that maternal anxiety probably moderates the child's responses to stressful situations through simple child modelling of parental anxiety. Kain et al., (2000) applied the framework to social learning theory to explain the pathway in which parental anxiety influences a child's response to anxiety provoking situations. They argue that parents can act as stress reducers for their children. Parents who are themselves more anxious in a given situation are less available to respond to their child's needs and his/her signals of increasing distress. Indeed, in these instances, a child's distress may further compound parental anxiety, thus rendering the parent increasingly less able to respond effectively.

Parental anxiety may be a surrogate marker for other factors that may influence a child's preoperative anxiety, such as parenting style and parental coping abilities. Given the recognition of the critical role that parents play in moderating children's preoperative experience, parent variables have received little attention in regard to its impact on children's preoperative anxiety. Although there are a number of studies assessing parent's anxiety, there is a paucity of studies evaluating any other parent variables that might correlate with children's preoperative anxiety. The next section reviews the research to date on other parental influences on children's preoperative anxiety and their theoretical backgrounds, focusing on the gaps in the research and areas for further investigation.

### **1.18 Parenting style**

The concept of 'parenting style' has been shown to be very robust in explaining how parenting practices relate to child outcomes (e.g. see Darling & Steinberg, 1993 for a review) and research on parenting style reveals a consistent picture of the types of parenting that maximally enhance socialisation of children (see Baumrind, 1991 for a review). However, parenting style has received little attention in regard to parent's impact on anxiety levels before children's medical procedures.

Research on parenting has identified three core dimensions, namely (a) the degree of parental responsiveness (e.g. warmth and support), (b) the degree of demandingness of the parent (supervision, rules/structure, and disciplinary efforts) (Baumrind, 1967; Maccoby & Martin, 1983), and (c) the promotion of autonomy (vs. overprotection) of older children and adolescents (e.g. Steinberg, 2010). The combination of responsiveness and demandingness led to the most often used typology of parenting styles (Maccoby and Martin, 1983): An authoritative parent balances high levels of demandingness with high levels of responsiveness. An authoritarian parent expresses high levels of demandingness and low levels of responsiveness. A permissive parent exhibits low levels of demandingness and high levels of responsiveness. Finally, a neglectful parent exhibits low levels of both demandingness and responsiveness.

Parenting dimensions and styles and the quality of the parent–child relationship play crucial roles in psychological development in general (Pinquart, 2013) and in the adaptation of children with chronic illness in particular, such as adherence to the medical regimen (e.g. Davis et al., 2001; Ellis et al., 2007). Many studies found that authoritative parenting contributes to children’s positive health behaviours (Tinsley et al., 2002). These positive effects are probably based on the promotion of a warm parent–child relationship, which leaves children more open for parental influences, and the promotion of self-reliance due to an appropriate balance of restrictiveness and autonomy support (Steinberg et al, 2010). In contrast, authoritarian and permissive parenting relate to poor child adjustment and health outcomes (e.g. Mullins et al., 2004). Generally, an authoritative parenting style has been found to be superior in promoting the children’s development of instrumental competence, whereas children of permissive parents show poorer self-regulation and instrumental competence.

Dahlquist et al. (1994) assessed the relationship between parenting style and child anxiety during the anticipatory phase of bone marrow aspiration or lumbar puncture. They found that 3 to 7 year old children who had parents that were less responsive and less nurturing were more distressed. Broome and Endsley (1989) found that children of authoritative mothers (defined as high in warmth and high in control) were

significantly less distressed during an immunisation than were children of authoritarian (low in warmth and high in control), permissive (high in warmth and low in control), or unresponsive (low in warmth and low in control) mothers. Drawing on this literature, it is reasoned that parenting style may influence children's levels of preoperative anxiety.

There is a limited literature examining the effect of parenting style on the child's anxiety and coping with surgery. Carson, Council and Gravley (1991) found that mothers who were more rejecting, overindulgent, and overprotective, had children who did not adjust well with hospitalisation (as measured by the mother child relationship evaluation (MCRE: Roth, 1980)). However, this study can be criticised because of major methodological limitations such a small sample size (n=47), inadequate measure for the outcome variable (the self-report Paediatric Patient Rating Scale shows limited validity and reliability (Vernon et al., 1966)), as well as homogenous sample, the entire sample consisted of Caucasian children from two-parent, middle- to upper middle-class families (Carson et al., 1991).

Brophy and Erikson (1990) examined 61 children between the ages of 5 and 11 years and found that parenting style was not found to be related to children's preoperative anxiety. Brophy and Erikson (1990) used the Child Development Questionnaire (CDQ: Zabin and Melamed, 1980) to measure parenting style. The CDQ was developed to assess the use of disciplinary methods by parents regarding their children's approach to fearful situations. Therefore the CDQ may not be a valid measure of parenting style (i.e. it may have been measuring a different construct) and according to Zabin and Maelamed (1980) the predictive validity of the scale was 'not satisfactorily established.' Furthermore, Brophy and Erikson (1990) state that 'the measures may not have adequately assessed the variables in question.'

However few conclusions can be made about the effect of parenting style due to the limited data, inadequate measures and their homogenous samples. It is possible that other samples of parents in modern surgery practices might not reveal the same

relations. More needs to be learned about the potential moderating role of parenting style on parents and children's preoperative anxiety.

### **1.19 Parental behaviours and coping style**

The anxiety experienced by parents and their ability to manage it is also related to the coping style adopted (Ibanga and Ibanga, 2009). Research suggests that coping strategies play an important role in the way that individuals respond to stressful situations and negative life events (Endler & Parker, 1990, 1999; Lazarus, 1993; Lazarus & Folkman, 1984; McCrae & Costa, 1986). Coping loosely refers to a person's ability to see problems as manageable, even in the face of situations being unpleasant and coping strategies are often used to mediate between antecedent stressful events and such consequences as anxiety, depression, psychological distress, and somatic complaints (Billings and Moos, 1981; Coyne et al., 1981; Endler & Parker, 1990, 1999; Parker & Endler, 1992).

Lazarus and Folkman's (1984) argue that cognitive appraisal and coping are two key processes in their theory of stress and coping. Lazarus and Folkman (1984) developed a process-oriented coping model that differentiated between two types of coping: task-oriented coping responses and emotion-oriented coping responses. Task-oriented coping responses involve attempts to alter the person–environment relationship. For example, in some situations one might create a plan to eliminate a stressor. Emotion-oriented responses involve attempts to regulate emotional distress. One might engage in cognitive restructuring wherein one redefines a situation to regulate emotional distress (Lazarus & Folkman, 1984). Later research uncovered a third coping strategy—avoidance coping (Endler & Parker, 1990, 1999). This strategy involves 'activities and cognitive changes aimed at avoiding the stressful situation' (Endler & Parker, 1999). The authors argue that these general types of coping are not mutually exclusive (Folkman & Lazarus, 1980). Most stressors elicit a combination of coping types (Endler & Parker, 1990). Nevertheless, research has found that people tend to use task-oriented coping strategies when they feel they can have an impact on the problem whereas they tend to use emotion-oriented coping when they feel that they must

tolerate the stressor (Endler & Parker, 1990; Folkman & Lazarus, 1980; Lazarus & Folkman, 1984).

There is evidence that some coping strategies tend to be more adaptive than others. A full review of the literature can be found in Schwarzer (1988). Although the coping strategies used also depend on the controllability of the situation (Conway & Terry, 1992), a task-oriented approach to coping with stressful events has been shown to lead to problem resolution or amelioration more often than an avoidance-oriented approach (Smith et al., 1990). Avoidance-oriented coping might indeed elevate the negative consequences of stressors, because by avoiding or trying to escape problems, the individual does not learn effective ways to solve them (Endler & Parker, 1990, 1999).

One study by Chorney, Torrey, Blount, McLaren, Chen, & Kain, (2009) examined the behaviours of anaesthesiologists, nurses, and parents during the induction of anaesthesia in children. They collected extensive digital video data on 293 2-10 year old children undergoing anaesthesia. They found that overall, adult emotion focused behaviours, such as empathy and reassurance, significantly predicted an increase in children's anxiety and reduction in children's coping behaviours. Whereas adult distracting behaviours, such as humour and distracting talk, predicted a reduction in children's anxiety and an increase in children's coping behaviours. Although this study can be criticised because it didn't consider potential moderators of effects (e.g., child temperament, previous surgical experience, parenting style), it provides preliminary evidence for a relationship between adult coping behaviours and children's anxiety and coping at anaesthesia induction.

In a parallel body of literature on children's procedural pain, the influence of adult behaviours on children's anxiety has also been studied. Specific behaviours such as talk about nonmedical topics (e.g. school and hobbies) and using humour have been found to be related to more coping in children undergoing painful medical procedures,

whereas behaviours such as reassurance and empathy have been found to be related to more anxiety (Dahlquist, Power & Carlson 1995).

Blount et al., (1989) examined 25 children between the ages of 5 and 13 years old who were diagnosed with acute lymphocytic leukaemia. Using the 'Child-Adult Medical Procedure Interaction Scale' (CAMPIS: Blount et al., 1989), they assessed the associations among 17 parent vocalisations and child behaviour. They found that certain adult behaviours were associated with child anxiety. Specifically they found that adults' reassuring comments, apologies to the child, giving control to the child, and criticising the child usually preceded child anxiety. On the other hand, child coping behaviours were associated with adult commands for the child to engage in coping behaviours, with nonprocedural talk with the child, and with humour. Based on these findings, Blount et al., (1990, 1997) revised the CAMPIS (CAMPIS-R) and formed two categories comprised of the individual parent behaviours: Adult Coping Promoting and Adult Distress Promoting.

However, these studies can be criticised because of the lack of controlling for predictive factors such as parenting style and child's anxiety in previous medical encounters (Blount et al 1989, 1990 and 1997). Furthermore, these studies examined children undergoing 'painful' procedures, such as bone marrow aspirations and with pre-schoolers receiving immunisations (Blount et al., 1989 and 1997). The findings, therefore, are not directly comparable to hospitalised children undergoing procedures under general anaesthetic.

Kain et al., (2006) carried out a large-scale prospective cohort study (n = 426) to identify child and parent characteristics that are associated with low anxiety and good compliance during induction of anaesthesia. The parent's baseline coping style was assessed using the Miller Behavioural Style Scale (MBSS: Miller, 1995). Although the authors found no significant effect of coping style on children's preoperative anxiety, they did find significant effect of parents who valued preparation and coping skills for medical situations (Kain et al., 2006). In a later study Kain et al., (2000) measured



parental coping style (using the MBSS) in a group of children undergoing surgery. Univariate correlational analysis demonstrated parental high-monitoring coping style was significantly associated with higher levels of perioperative anxiety. However when this was entered into multivariate analysis these findings were no longer significant. Lack of significance in these studies may be due to methodical limitations such as inappropriate measures of coping style. Several researchers have reported that the internal consistency of the 'blunting' scale of the MBSS sometimes falls below acceptable limits (e.g. Miller, 1992).

In short, research has revealed that parent behaviours are highly associated with child distress behaviour. Specifically, parents' reassuring comments, giving the child behavioural control, apologising, empathetic comments, and criticism have been shown to be significantly positively associated with children's procedural distress. On the other hand, parents' distracting comments and commands to engage in coping have been shown to predict increased child coping and decreased procedural anxiety.

To date, parental coping style has not been assessed as a variable to consider when examining risk factors for children's anxiety. More needs to be learned about the impact of parental coping style on child anxiety during the preoperative period. If we identify that parental coping style is related to children's preoperative anxiety then interventions can be tailored not only to those children at risk, but also so that they are congruent with their parent's coping styles. For example, providing those who respond with a task oriented strategy with information and elaborating on the medical equipment and procedure may help alleviate some of these anxieties. This approach, however, would have the opposite effect for those who respond with an emotion-focused coping style. For those parents, it may best to build in activities that would enable deliberate avoidance or refocusing (distraction) from the procedure.

## 1.20 Section Summary

The relationship between parental variables and children's anxiety and coping is relevant to theoretical models which attempt to shed light on the risk factors for

children's preoperative anxiety. This review indicates significant gaps in current knowledge about parent's preoperative experience in relation to children's anxiety and further studies are needed using adequate experimental designs and methods. Therefore, given the paucity of studies looking into the influence of parental variables on children's preoperative anxiety, this study aims to apply rigorous methodology, good experimental design and to use a more heterogeneous sample. This study aims to further explore the complex relationship between parent and child preoperative anxiety by assessing other parental factors, such as parenting style and parental coping style, which may act as potential moderators of effect.

### **1.21 Theoretical framework**

The development of a theoretical framework is essential as it identifies, defines and operationalises constructs and concepts, develops relational statements and expresses the statements in a hierarchical style. Theories of stress and coping, although not always explicitly stated, appear to be the most widely referred to in the field of children's hospitalisation and illness.

Other theories identified from the literature have related to either the parent (self-regulation theory, control theory) or the child (crisis theory, developmental theory, social learning theory/emotional contagion hypothesis). It is not within remit of this project to describe each of these theories, for a more detailed description refer to the review by Goslin (1978).

It is possible that elements of other theories exist within a framework of stress and coping, e.g. the high correlation between parent and child preoperative anxiety could be explained in terms of social learning theory. For example, Seagull (2000) stated that parents may serve as resources to support and scaffold children's coping, parents may serve as important models of effective and ineffective coping for their children, and parent's who are ineffective in coping with the stress of their child's illness may contribute to increased distress in their children.

Parents and children enter the stressful encounter with or without personal experience, preparation and information about the surgery. These and other personal factors such as child developmental stage and temperament, parental education and socioeconomic status all influence how the stress is appraised. Immediate coping outcomes are evidenced by child and parent preoperative anxiety levels. In the context of the theoretical framework child and parent anxiety are considered to be immediate outcomes of coping. Heightened child/parent anxiety are indicative of poor coping during the stressful event, which is either improved or worsened by additional factors that the dyad are exposed to prior to and after the child's surgery.

In a systematic review of the literature Power et al., (2010) found only one study that explicitly stated the theoretical framework on which the research was based (Brewer et al. 2006). Based on Lazarus and Folkman's theory of stress and coping (Lazarus et al. 1984), Brewer, Gleditsch, Syblik, Tietjens & Vacik (2006) explained how the stressful events of admission to hospital for surgery, i.e. separation from family, fear of the unknown, loss of control and fear of pain contribute to a child's anxiety both before and after hospital and the child's cognitive appraisal of the event determines coping behaviours. Factors such as child age, developmental level, prior hospitalisations and prior encounters with the medical profession, child and parental coping styles and parenting style affect coping behaviours (Brewer et al. 2006). Lazarus and Folkman's theory of stress and coping (Lazarus et al. 1984) is a suitable theory to explain the stressors that the parent-child dyad are faced with in the preoperative period and how their appraisal of the stress affects coping strategies, and immediate and long-term coping outcomes.

This theory has been supported through evidence from intervention studies that have attempted to improve child coping and/or to minimise their exposure to stressful stimuli, with positive child preoperative anxiety and post-discharge behavioural outcomes. Factors that influence children's cognitive appraisal of the stressful event of hospitalisation for surgery and their coping were discussed in relation to theory. The

study methodology, i.e. the study design, the participants and the setting were chosen as the most appropriate to address the specific study objectives.

### **1.22 Preparation before surgery**

Due to the immediate and potentially more long-term negative effects of preoperative anxiety, researchers have sought out prevention and intervention strategies to alleviate anxiety and decrease the development of negative behaviours post operatively (Wright et al., 2007). A number of prevention strategies have been employed. Both pharmacological (e.g. sedative) and non-pharmacological (e.g., behavioural preparation programs, music and acupuncture) approaches have proven useful.

#### **Pre-medication**

Administration of benzodiazepines, such as midazolam, has been shown to reliably reduce children's anxiety before surgery. However, administration of premedication may be associated with increased operational hospital costs, potential operating room delays, and slower discharge from the recovery room in patients undergoing minimally invasive surgical procedures (Watson & Visram, 2003).

#### **Preparation programs**

Preparing the child and his or her family for a procedure has long been considered appropriate practice, and a number of studies have shown that adequate preoperative preparation can reduce anxiety for surgery (Kain, 2005).

Many approaches have been used to deliver preoperative information to educate children and parents that focused on preoperative preparation of children with the apparent aim of enhancing their coping skills. These studies involve exposure of the child to surgery-related stimuli such as information leaflets (Bellew Atkinson, Dixon & Yates, 2002), interactive books (Margolis, Ginsberg, Dear, Ross, Goral & Bailey, 1998), videos (McEwen, Moorthy, Quantock, Rose & Kavanagh, 2007) and tours of the facility have been shown to have a positive but variable impact on preoperative anxiety.

Given the recognition that a significant proportion of parents experience high levels of preoperative anxiety (Kain et al., 2009) and this may be related to increased children's preoperative anxiety (e.g. Cagiran et al., 2014), researchers have concluded that interventions must target parents in addition to children (e.g. Kazak & Barakat, 1997). Furthermore, parental anxiety is a relevant concern in its own right. Although various interventions are routinely used to reduce a child's anxiety, there is a paucity of information regarding interventions directed toward reducing parental anxiety and widespread adoption has not been recommended nor delivered (Kain, 1999).

Researchers have implemented stress-inoculation (e.g., Zastowny, Kirschenbaum & Meng, 1986; Jay & Elliott, 1990) and provided parents with coaching roles (e.g. Cohen et al., 1997). Jay and Elliot (1990) developed a stress inoculation program specifically designed to reduce parental anxiety during their children's oncology procedures. This program included watching films that provided modelling of appropriate coping behaviours and education about leukaemia, self-statement training, and relaxation training. Results of this study provided initial evidence for the efficacy of the stress inoculation program for decreasing parent anxiety. However the impact of the intervention on children's perioperative experience was not provided.

Researchers have developed programs designed for parents with the hypotheses that lowering parent anxiety would result in lower child procedural anxiety and pain. Although this makes conceptual sense, there are no published data that support this directional hypothesis. However, careful investigation of the relations among parent variables and child preoperative anxiety might shed some light on directional relations.

More recently, Kain et al., (2009) developed a behaviourally oriented perioperative preparation program for children undergoing surgery that targets the family as a whole. The 'ADVANCE' program integrated psychological principles of shaping, exposure, and modelling with coaching and distraction interventions (Kain et al., 2007). ADVANCE was shown to be effective in the reduction of preoperative anxiety and improvement in postoperative outcomes such as reducing emergence delirium

(Kain et al., 2007). This study provides provisional support for the notion that parents who are less prepared are unable to accurately appraise the stressful event of the child's hospitalisation for surgery, resulting in poorer coping outcomes for the parent and the child. A major disadvantage of ADVANCE, however, is its high cost and personnel requirements which preclude widespread adoption (Yuki & Daaboul, 2011).

### **1.23 'Assessment before intervention'**

Kain et al., in 2009 stated that the majority of preoperative preparation programs in children are unstructured, out-dated, and unsupported by reliable, valid outcome data (Kain et al., 2009). Furthermore, where studies have documented the effectiveness of interventions in reducing children's anxiety and facilitating recovery (e.g. Elkins & Roberts, 1983) practical implementation of research findings, however, have been limited. Kain et al., (2009) suggest that many hospitals use only relatively weak preparations such as tours or colouring books, and only a minority of children are included (Peterson & Ridley- Johnson, 1980; Peterson, Ridley-Johnson, Tracy & Mullins, 1984). Lumley et al., (1993) found that many hospitals have discontinued preparation programs altogether, secondary to shortages of hospital personnel, time, and money, and a concern about effectiveness.

Mitchell (2002) argues that the delivery of effective psycho-educational care in preparing patients for surgery in the UK seldom takes place. Although Surgical and anaesthetic intervention associated with surgery over the last 10 years has greatly improved Kleinbeck (2000) asserts that the position of psychological preparation has remained virtually unchanged and psycho-educational aspects of care have become considerably marginalised.

The discrepancy between optimistic research findings and their disappointingly limited implementation may be aggravated by an assumption that all children need comprehensive preparation (Melamed & Ridley-Johnson, 1988). Not only do limited hospital resources and staff limitations render this goal unfeasible, but also many

unprepared children appear to experience little or no preoperative anxiety, making preparation of questionable value in such cases (Beeby & Morgan-Hughes, 1980).

Kain and Caldwell-Andrews (2005) indicate specific factors that are important to consider when designing a preparation program. These variables include child age, timing relative to surgery, and the child's previous hospitalisation history. For example, a preparation program that is appropriate for a 3 year old may not be appropriate for a 12 year old. The timing of the particular preparation program prior to the surgery has been identified as a significant factor as well. For example, participation in a preparation program more than 5 to 7 days prior to surgery has been found to be most beneficial for children 6 years and older and the least beneficial when the program is given 1 day before surgery (Kain et al., 1996; Melamed, Meyer, Gee, & Soule 1976; Robinson & Kobayashi, 1991).

However, as described here, there are few current studies investigating risk factors for children's preoperative anxiety. Reviews of studies investigating possible risk factors for children's preoperative anxiety conclude they are sparse, show inconsistent findings and vary according to the methodology implemented (Ahmed et al., 2011). Furthermore previous studies have not been able to incorporate parent variables into one study. In many day surgery settings, responsibility for preparing children for surgery rests with the parents, (Ellerton & Merriam, 1994). With the increasing use of day surgery, preparation of both parents and children takes on increasing importance.

#### **1.24 The current study**

There is a compelling need to develop and evaluate psychological interventions that can enhance children's and parents' ability to cope with surgery. However, before treatment outcome research can be carried out proper assessments need to have been conducted. This study seeks to ascertain those risk factors in the preoperative period that may lead to increased children's preoperative anxiety. Parental preoperative anxiety has been identified as a significant predictor for preoperative anxiety (e.g. Kain, 1996). Parental state anxiety, however, may be a surrogate marker

for other factors that may influence a child's preoperative anxiety. These include parental coping style, parenting style and parent's trait anxiety. Thus, there is a need to assess directly the relationship between parental coping style, parenting style and parents' trait anxiety with children's preoperative anxiety. Specifically, this study intends to broaden the perspective of research into children's preoperative anxiety and investigate parent-child psychological risk factors that may moderate children's preoperative anxiety. This will provide an up to date theoretically driven research attempting to identify those children 'at risk' of developing high levels of preoperative anxiety. In doing so, it is hoped that potential risk factors may be found, which may be targeted in future interventions.

### **1.25 Aims of the current study**

1. To investigate whether the prevalence rates of preoperative anxiety in children admitted for elective minimal stay surgery, and their parents, are similar to previous incidence estimates.
2. To investigate the association between child self report and parental proxy report children's preoperative anxiety.
3. To investigate whether certain child, parental and in-hospital factors are related to children's preoperative anxiety and investigate whether risk factors for children's preoperative anxiety can be identified;
  - a. To investigate whether socio-demographic (e.g. ethnicity, parents occupation and parents gender) and in-hospital setting factors (e.g. type of procedure, how long the child has waited for the operation and how many people accompanied the child to hospital) are related to children's preoperative anxiety.
  - b. To investigate whether previous variables that have shown to predict children's preoperative anxiety in previous research (previous predictor variables) are related to children's preoperative anxiety. Specifically we aim to establish whether child's age, the quantity of previous



hospitalisations, the quality of previous hospitalisations and parental preoperative anxiety are predictive of children's preoperative anxiety.

- c. To investigate whether parental trait anxiety, parental coping style, and parenting style are related to children's preoperative anxiety.

### 1.26 Hypotheses

1. The proportions of children and parents experiencing high levels of preoperative anxiety will be similar to rates found in previous studies.
2. There will be a significant association between self-report, parent report and examiner observational measures of children's preoperative anxiety.
3. There will be a significant association between socio-demographic variables and children's preoperative anxiety. There will be a significant association between in-hospital setting variables and children's preoperative anxiety.
4. There will be a significant association between previous predictors of children's preoperative anxiety and children's preoperative anxiety. Based on previous research it is expected that there will be a significant positive association between parent's preoperative anxiety and quantity of previous hospitalisations and children's preoperative anxiety and a significant negative association between the quality of previous hospitalisations and children's preoperative anxiety. The effect of child's age on children's preoperative anxiety has been shown to be inconsistent therefore the direction of the effect of child's age on children's preoperative anxiety will be exploratory.
5. There will be a significant association between parent variables and children's preoperative anxiety:
  - a. There will be a significant association between parental coping style and children's preoperative anxiety. It is expected that parents with a task-orientated coping style will be related to lower preoperative anxiety in their child compared to parents with an emotion-orientated or avoidance coping style whose children will be more anxious.

- b. There will be a significant association between parenting style and children's preoperative anxiety. Based on previous literature in the area of parenting style, it is expected that an 'authoritative' parenting style will be related to lower preoperative anxiety, whereas 'permissive' parenting and 'authoritarian' parenting styles will be related to higher preoperative anxiety.
- c. There will be a significant association between parent's trait anxiety and children's preoperative anxiety. Based on the previous research it is expected that there will be a positive relationship between parental trait anxiety and children's preoperative anxiety.

## 2 Methods

### 2.1 Materials and Methods

This study used a cross-sectional correlational design in a population of children aged 3-12 years old who underwent general anaesthesia and elective surgery at the Evelina London Children's Hospital and their parents. It was designed to test for relationships occurring between child, parental and in-hospital predictive variables and children's preoperative anxiety. The dependent variable was children's preoperative anxiety determined using the examiner observational measure the modified Yale Preoperative Anxiety Scale (m-YPAS), and according to children's self-reported anxiety and parent proxy report of children's anxiety using the Visual Analogue Anxiety scale measures. The independent variables were 1) Socio-demographic factors, 2) in-hospital setting factors, 3) Parent's anxiety, 4) Parental coping style and 5) Parenting style.

### 2.2 Ethical Approval

The study was approved by the Health Research Authority, National Research Ethics (NRES) Committee London, Queens Square, reference 13/LO/0498 on 17th May 2013. It was also approved by Guy's and St Thomas' Foundation Trust Research and Development Department; reference RJ113/N194 on 26th July 2013 (see Appendix 1).

### 2.3 Power Analysis and recruitment feasibility

A power analysis was conducted using 'nQuery Advisor' to determine the sample size required to find moderate correlations between the independent and dependent variables. As no previous studies have examined parenting style and parental coping and child's preoperative anxiety, previous studies reporting correlations between measures of parent anxiety and child preoperative anxiety were used as a guide to the power calculation. A previous study of 163 children (and their parents), who underwent general anaesthesia and elective surgery (Kain et al., 1996) used a hierarchical multiple regression model to examine the relation between child's preoperative anxiety and possible predictive variables. The main outcome variables were the anxiety level of the child and parents determined using self-reported and

independent observational Visual Analogue Scale (VAS) measures in the preoperative period. State anxiety of the parents was also assessed using the State Trait Anxiety Inventory (STAI) (Spielberger, Gorsuch & Lushene, 1970). Kain et al., (1996) showed that children of anxious parents ( $r^2=0.12$ ,  $F=4.3$ ) demonstrated higher levels of anxiety in the preoperative period. Based on this study, it was considered a reasonable assumption that parental anxiety might account for around 12% of the variance ( $r^2$ ) and the relationships between the potential parental predictors and the child's preoperative anxiety would be in the moderate range.

For a multiple linear regression model that already includes three covariates (parental coping, parenting style and child's age) assuming the current study would find moderate correlations of  $r^2 = 0.075$  at a significance level of  $p = .05$ , a sample size of 89 would provide 80% power to detect such correlations. It was considered that a sample size of 89 would be large enough to account for the 4 predictors effect on the variance. Should more covariates be added to the calculation (e.g. sociodemographic and in-hospital setting factors) then a smaller sample size would be required as it is expected that these factors would explain more of the variance.

## 2.4 Participants

Participants were identified at the Ear Nose and Throat (ENT) and Cleft Lip and Palate (cleft) pre-admission clinic (PAC) by the care team. The PAC is a nurse-led outpatient appointment for all children referred by their consultant for an operation which involves a general anaesthetic. The general PAC takes place at the Evelina London Children's Hospital and all children under ENT and their parents are required to attend this clinic up to four weeks before the child's scheduled operation. The cleft PAC runs separately, it takes place every Thursday and all children under the cleft service and their parents are required to attend this clinic up to four weeks before the child's scheduled operation.

**Inclusion criteria**

Children aged three to twelve years old undergoing general anaesthesia and elective surgery at the Evelina London Children's Hospital and their main caregiver were invited to take part in the study. The study population was drawn from Ear, Nose and Throat (ENT) surgical specialty (including grommet insertion, auditory implants, adenoids and tonsils) and Cleft Lip and Palate (cleft) surgical specialty (including those having alveolar bone grafts) as well as those children undergoing general anaesthesia for imaging procedures (MRI and CT scans) under ENT. As this study employed a naturally occurring population, some children stayed in the hospital accommodation the night before the procedure, some children stayed in hospital as minimal stay inpatients after their procedure, whereas other children were there as day case patients only. Children with a learning disability were included in the study, as it was considered that to exclude such children would limit the applicability of the study findings.

**Exclusion criteria**

Children and parents who did not speak English were excluded from the study as there were not adequate means of translating either the measures or the face to face contact on the ward into the participant's or their caregiver's language. Children undergoing life saving or emergency procedures were excluded from the study as it was considered that different concerns and levels of anxiety may be present in such children and their families. It was also considered that it would be unethical to approach these families at such a difficult time in their lives. The findings will be limited to children having elective surgeries.

**2.5 Measures used to assess children's preoperative anxiety****The Dependent Variable**

The modified-Yale Preoperative Anxiety Scale (m-YPAS) (Kain et al., 1997): Observer administered

The modified-Yale Preoperative Anxiety Scale (m-YPAS) (Appendix 3) is an observer-rated scale designed to measure the level of anxiety experienced by children aged 2-12

years in the preoperative setting. This scale determines a child's level of anxiety by evaluating a series of behaviours from calm to severe. The m-YPAS consists of 22 items in five categories of activity (e.g. moving from toy to parent in an unfocused manner), vocalisations (e.g. whimpering, crying), emotional expressiveness (e.g. worried, sad, or frightened eyes), the state of apparent arousal (e.g. vigilant, looking quickly all around), and the use of parents (e.g. child reaches out to parent). The highest behavioural level observed in each of the five m-YPAS categories is the score for that category. Because each category of the m-YPAS has a different number of items (either four or six), partial weights are calculated and then added to form a total score that ranged from 0 to 100. For example, for two categories containing four and six items, with a score of 1 in each category, the calculation is:  $(1/4 + 1/6) \times 100/2 = \text{total adjusted score}$ . Scores range from 22.5 to 100 with higher scores indicating greater anxiety.

The m-YPAS has shown good concurrent validity ( $r=0.64$ ) (Kain et al., 1996), construct validity (e.g., Finley et al., 2006; MacLaren & Kain, 2008; Wright et al., 2010), and good to excellent inter- and intra-observer reliability ( $r=0.73-0.91$ ) (Kain et al., 1996). This measure was developed and validated in previous investigations and has since been used in multiple experimental protocols. In this study a m-YPAS score of greater than 30.0 was used to classify patients with high anxiety and this cut-off has been used to differentiate groups of high anxiety ( $<30/100$ ) of children (Kain et al., 1997).

The observer-rated m-YPAS (Kain et al. 1997) is widely used in the day surgery setting to assess child anxiety. However, observational measures in clinical practice can be time consuming to administer and score, and require training (e.g. Goodenough, Piira, Von Baeyer, Chua, Wu, Trieu, & Champion 2004). Indeed, in clinical settings research shows that both health care personnel and families rely on their own judgment and nonspecific factors to make decisions about the need for a preoperative intervention, such as sedative premedication, for a particular child (MacLaren et al., 2009). For this study to be applicable to everyday clinical practice it was felt that it may be advantageous to have additional measures of children's preoperative anxiety.

Additional measures of children's preoperative anxiety were chosen to examine the ability of children and their parents to assess children's preoperative anxiety compared to the m-YPAS.

### **Inter-rater reliability**

In the current study the observer ratings of the m-YPAS was administered by a trainee clinical psychologist and two undergraduate medical students taking an intercalated degree in psychology. They were trained to reliably administer the m-YPAS. Training of the m-YPAS involved didactic trainings, in vivo observation and bi-weekly meetings with a Clinical Psychologist. All raters completed a measure for five children to enable comparison and had high reliabilities, intraclass correlation coefficient showed an 'excellent' correlation ( $ICC = .766$ ,  $P < .001$ ). Fleiss (1981) and Cicchetti and Sparrow (1981) define reliability measures as:  $<0.40$  = Poor;  $0.40-0.59$  = Fair;  $0.60-0.74$  = Good; and  $0.75$  and above = Excellent.

### **The Visual Analogue Scale (VAS)**

The Visual Analogue Scale (VAS) is a 100mm horizontal line that pictorially represents 2 behavioural extremes at either end of a continuum. Scores ranged from 0 to 100, with higher scores indicating higher levels of subjective states. The VAS has been widely used to assess general anxiety (Davey, Barratt, Butow & Deeks 2007) preoperative anxiety (Kindler, Harms, Amsler, Ihde-Scholl, & Scheidegger, 2000) and pain (McGrath, 1990) and does not show the clustering of responses that is typical of Likert-type scales (MacLaren et al., 2009). Sherman, Eisen, Burwinkle and Varni (2006) demonstrated test-retest and internal consistency reliability as well as construct validity in a VAS anxiety instrument for both child self-report and parent proxy-report in the medium to large effect sizes. A VAS has been validated to measure anxiety (VAS-anxiety) in children (Bringuier et al., 2009), adolescents (Fortier, Martin, MacLaren, Chorney, Mayes & Kain, 2011) and adults (kindler et al., 2000). In this study, a VAS-anxiety score of 30.0 was used as a threshold to detect high levels of anxiety in both children and their parents. This cutoff has been used in previous studies to differentiate groups of

high anxiety (<30/100) of children and parents with 78% sensitivity and 67% specificity (Bringuier et al., 2009).

#### The Visual Analogue Scale – Anxiety Self-Report (VAS-Child): Child administered

There is no gold-standard 1-item self-report measure of anxiety/fear in children (McMurtry et al., 2011). The Children's Anxiety and Pain Scales (Kuttner & LePage, 1989) are often used; however, its acceptability to children and parents is low (Chambers, Hardial, Craig & Montgomery, 2005). Faces scales are commonly used in pain studies with young children (Champion et al., 1998) and have been shown to be valid and reliable for measuring child anxiety (e.g. Sherman et al., 2006). The Children's Fear Scale (CFS) developed by McMurtry, Chambers & McGrath (2010) is based on the Faces Anxiety Scale developed by McKinley et al., (2003) to measure anxiety or fear in adults in the intensive care unit. The one-item scale consists of a row of five, sex-neutral faces ranging from a no fear (neutral) face on the far left to a face showing extreme fear on the far right. The rater responds by indicating which of the five faces matches his or her level of anxiety or fear. The scale faces were drawn by a graphic artist based on photographs of faces exhibiting fear, together with detailed descriptions of how facial muscles change as fear intensifies (Ekman & Friesen, 1975).

Research has shown support for inter-rater reliability ( $r = .51$ ) and test-retest reliability ( $r = .76$ ) of the CFS for measuring children's fear during venepuncture (McMurtry et al., 2010). Assessment of construct validity revealed high concurrent convergent validity with another self-report measure of fear; The Children's Anxiety and Pain Scales (Kuttner & LePage, 1989) ( $r = .78$ ) and The Faces Pain Scale - Revised (Hicks et al., 2002) ( $r = .60$ ). In terms of convergent validity, the FAS obtained moderate discriminate validity with child coping behaviour and with child distress behaviour (McMurtry et al., 2010) ( $r = -.30 - .41$ ). However, few existing instruments use faces to measure anxiety in children (McMurtry et al., 2010). Although research shows that children prefer faces scales as a simple self-report measure (e.g. McKinley et al., 2003), more studies are required to prove the validity and reliability of the limited anxiety scales that currently



exist (Kuttner & LePage, 1989). The Visual Analogue Anxiety Scale (VAS-Anxiety) has been validated to assess perioperative anxiety in children 7 years and older (Bringuier et al., 2009). In terms of convergent validity the VAS-anxiety correlated significantly with the m-YPAS ( $r=0.67$ ) in children younger than 12 years (Bringuier et al., 2009).

There is no clear consensus on the best approach to obtaining self-report from children (Chambers & Johnston, 2002). However, simplified wording/instructions, concrete response options, and an option for the rater to respond nonverbally are important developmental considerations (Sattler, 2002). Pairing a picture with a scale has been suggested as a useful assessment technique (McMurtry et al., 2011). The paired VAS measure has been used in other research requiring children to give self-reported estimates of preoperative pain and anxiety (e.g. Goodenough, Thomas, Champion, Perrott, Taplin, von Baeyer & Ziegler 1999). Therefore, in this study the VAS-anxiety was paired with the faces scale pictures (taken from the CFS scale (McMurtry et al., 2011)) to measure children's self-reported anxiety.

Bringuier et al., (2009) study showed children aged 7 years and above are able to accurately assess their preoperative anxiety using the VAS. Based on these findings In this study the VAS-Anxiety Self-Report measure (VAS-Child) (Appendix 4) was administered to children aged 7-12 years old. The VAS-Child consisted of a 100-mm horizontal line with the two end points labelled "no anxiety or fear" and "worst possible anxiety or fear" supplemented with computer-generated faces above the line. Each of the faces was described according to the written instructions in a thorough and systematic fashion. Children were then asked to show the point that corresponds to their level of fear/anxiety at that moment. Ratings were scored with a ruler yielding a score ranging from 0 to 100 with higher scores indicating higher anxiety.

#### The Visual Analogue Scale – Anxiety Parent Proxy Report (VAS-Proxy): Parent administered

The VAS-anxiety has also been used to ask parents about children's distress (e.g. Bringuier et al., 2009; MacLaren, 2009). In the present study the parent was asked

“compared with same age children, how distressed does your child appear?” The VAS-Proxy (Appendix 5) consisted of a 100-mm horizontal line with the two end points labelled “Not distressed at all” and “Extremely distressed.” Parents were asked to make a vertical mark along the VAS that corresponded to the point between the two anchors that reflected their response to the question. Ratings were scored with a ruler yielding a score ranging from 0 to 100 with higher scores indicating higher anxiety.

Previous research has demonstrated that parents tend to overestimate the child’s experience compared to the child’s assessment (Bringuier et al., 2009; Maclaren et al., 2009). In addition, proxy-reporting scores are higher when parents are anxious (Bringuier et al., 2009). However, few studies have measured the accuracy of parent predictions of children’s preoperative anxiety and further research is needed to investigate the validity and reliability of this method. Given the difficulties in everyday clinical practice of assessing children’s preoperative anxiety, as well as the limited data on the accuracy of parent proxy report, it was decided it would be advantageous to supplement the children’s preoperative anxiety measures with the VAS-Proxy.

## 2.6 Independent Variables

### The Visual Analogue Scale – Anxiety Adult Self-report (VAS-Adult): Parent administered

The linear VAS is commonly used to assess adults preoperative anxiety (Oldman, Moore & Collins, 2004). In addition, parents own anxiety can be examined in this same manner (Cohen, Blount & Panopoulos, 1997). The VAS-anxiety adult self-report (VAS-Adult) (Appendix 6) consists of a 100-mm horizontal line with the two end points labelled “no anxiety or fear” and “worst possible anxiety or fear.” In the present study, parents were asked to show the point that corresponded to their level of anxiety at that moment. The VAS anxiety correlates well with other anxiety measures  $r = 0.60$  ( $p < 0.0001$ ) with the Hamilton Rating Scale for Anxiety and  $r = 0.74$  ( $p < 0.0001$ ) with the Hospital Anxiety and Depression Scale - Anxiety subscale (Williams, 20010) and  $r = 0.67$  ( $P < 0.001$ ) with the STAI (Bringuier et al., 2009). In terms of convergent and divergent validity, the VAS anxiety obtained relatively high correlations with the Hamilton Rating

Scale for Anxiety and Hospital Anxiety and Depression Scale - Anxiety (Sherman et al., 2009). The VAS-anxiety measure was selected as measure of state anxiety in parents due to its wide use in previous investigations, where it has shown to have good psychometric properties and validity (Bringuier, 2009). Unlike the STAI (Spielberger et al., 1970), which takes five to ten minutes to complete, the VAS-anxiety has the advantage of being simple to explain to patients, and quick and easy to administer and only takes a few moments to complete. The constraints on time and patient overload were also considered and it was decided that the VAS-anxiety instead of the STAI state should be administered.

#### The State-Trait Anxiety Inventory (STAI) trait subscale (Spielberger et al., 1970): Parent administered

The State-Trait Anxiety Inventory (STAI) (Appendix 7) is a self-report measure consisting of a 20-item state anxiety scale (how one feels right now) and a 20-item trait anxiety scale (how one generally feels) (Spielberger et al., 1970). In this study the trait form of the State-Trait Anxiety Inventory was used to assess parents' general level of anxiety. The STAI trait subscale measures relatively stable individual differences in anxiety proneness (i.e. differences in the tendency to experience anxiety) (Spielberger, et al., 1970). The trait anxiety scale of the STAI consists of 20 self-report items to which respondents are asked to indicate to what degree the item describes their feelings on a four-point Likert-type scale (where 1 = "not at all" and 4 = "very much so"). High scores on this measure are indicative of high levels of anxiety. The STAI has appeared in over 3,000 studies and has been translated into over 30 languages (Spielberger, 1989). In an investigation of the reliability generalization of the STAI, the measures demonstrated excellent internal consistency (average  $\alpha$ 's = .89), and the STAI Trait has evidenced excellent test-retest reliability (average  $r$  = .88) at multiple time intervals (Barnes, Harp, & Jung, 2002). The measures have evidenced adequate convergent and discriminate validity with other measures of state and trait anxiety and have been shown to differentiate patient from control samples on the STAI Trait (Spielberger, 1983). Internal consistency coefficients for the scale have ranged from

.86 to .95; test-retest reliability coefficients have ranged from .65 to .75 over a 2-month interval (Spielberger, 1983). Considerable evidence attests to the construct and concurrent validity of the scale (Spielberger, 1989).

The Coping Inventory for Stressful Situations: Situation Specific Scale (CISS:SSC) (Endler & Parker, 1999): Parent administered

The Coping Inventory for Stressful Situations: Situation Specific Scale CISS:SSC (Endler & Parker, 1999) (Appendix 8) is a 21-item, self-report instrument measuring problem-focused coping, emotion-focused coping, and avoidance-oriented coping in a specific situation (in this case waiting for their child's operation). Using a 5-point frequency rating scale, respondents indicate how much they engage in certain coping behaviours related to this specific situation. Factor scores are obtained for each of the 7-item scales and range from 7 to 35. High scores indicate a higher degree of commitment to a particular coping style. The CISS:SSC was developed by modifying the Coping Inventory for Stressful Situations (CISS: Endler & Parker, 1990), which measures general coping style. The CISS:SSC items are a subset of the CISS items. To create the CISS:SSC, the developers used a large normative sample of college students and eliminated the CISS items with the lowest item-total correlations.

The CISS:SSC (formerly called the Multidimensional Coping Inventory (MCI; Endler & Parker, 1990)) was developed using a rational-empirical approach. It is built upon the theoretical tradition of Lazarus and Folkman's work (Folkman & Lazarus, 1980, 1985, 1986, 1988) with the structures of task-focused and emotion-focused coping. The CISS developers also include the dimension of avoidance-oriented coping. Avoidance-oriented coping relates to theoretical constructs such as Bruner and Postmani's (1947) perceptual defense, Byrnes (1961) repression-sensitisation, and Krohne's (1986) attentional diversion (Endler & Parker, 1999). According to Endler & Parker (1990, 1990) task-oriented coping refers to responses directed at either problem resolution or cognitively reframing the meaning of the stressful situation. Emotion-oriented coping refers to responses directed toward oneself rather than the problem at hand.

Avoidance-oriented coping refers to responses designed to avoid dealing with the stressful situation. Such attempts to deal with stress may take the form of either distracting oneself with other situations (e.g., shopping) or through interacting with other people (Endler & Parker, 1990, 1999).

Internal consistency coefficients for the factors on the CISS:SSC ranged from .73-.92 with most correlations above .80. Test-retest reliability coefficients were reported at .51-.73. Construct validity is supported through correlations with other coping measures, such as the Ways of Coping Scale (Folkman & Lazarus, 1980), the Eysenck Personality Inventory (Eysenck & Eysenck, 1975) and the Basic Personality Inventory (BPI Jackson, 1989). Internal alpha reliability coefficients for the CISS:SSC range from .70 to .84 (Endler and Parker 1994). Endler and Parker (1994) examined the correlation between the CISS and the CISS:SSC to determine convergent and discriminant validity. Moderate to high correlations were found between the task scales, between the emotion scales, and between the avoidance scales on the two instruments (Endler & Parker, 1994).

While the CISS:SSC has various norm groups to score against, e.g., Social Evaluation, Change in Social Situation, and Interpersonal Conflict, none of those categories seem to match well the situation of waiting for an operation. Thus, in this study, raw scores were used in the analysis. For a general understanding of the sample, the scores were also compared to norm scores based upon an adult normative sample who described how they experience stress in general, in accordance with the test manuals instructions for scoring the CISS:SSC (Endler & Parker, 1999).

Parental Authority Questionnaire-Revised (PAQ-R) (Reitman, 2002): Parent administered

The Parental Authority Questionnaire-Revised (Appendix 9) provides a measure of parenting style (PAQ-R; Reitman, 2002). The 30 item questionnaire, which consists of three subscales and measures authoritative (e.g. "Once family rules have been made, I discuss the reasons for the rules with my children"), authoritarian (e.g. "When I ask my

children to do something, I expect it to be done immediately”) and permissive (e.g. “In a well-run home children should have their way as often as parents do”) parenting styles. The PAQ-R (Reitman et al., 1997) is a modified version of Buri’s (1991) Parental Authority Questionnaire and is designed to provide a brief and accurate measure of the extent to which parents hold parenting attitudes consistent with Baumrind’s parenting typologies: authoritativeness, authoritarianism, and permissiveness (Baumrind, 1971). Readability for the PAQ-R was estimated at the fifth-grade level (aged 10-11 years) by the Grammatica software program (Reference Software International, 1986). The current version of the scale consists of 30 items rated on a 5-point scale (from strongly disagree to strongly agree). Factor scores are obtained for each of the 10-item scales and range from 10 to 50. High scores indicate a higher degree of commitment to a particular parenting style.

In a United States college student sample, Buri (1991) reported Cronbach’s alpha values in the acceptable range across all subscales (mother authoritarian .85, mother permissive .75, mother authoritative .82, father authoritarian .87, father permissive .74, and father authoritative .85). Two-week test-retest reliability estimates for mothers’ and fathers’ parenting styles ranged from .77 to .92 (Buri, 1991). Reitman et al. (2002) reported modest values of Cronbach’s alpha for the three PAQ-R subscales (authoritarian .72, permissive .76, and authoritative .77). One month test-retest reliability was considered adequate (authoritarian .87, permissive .67, authoritative .61) (Reitman et al., 2002). Convergent validity was established through comparing the PAQ-R to the Parenting Scale (PS: Arnold, O’Leary, Wolff, & Acker, 1993) and the Parent-Child Relationship (PCRI) Questionnaire (Gerard, 1994). The authoritarian scale was correlated with the Over-reactivity subscale of the PS ( $r = .24, p < .001$ ) and the Communication subscale of the PCRI ( $r = .25, p < .001$ ). The authoritative scale was correlated with the Communication subscale of the PCRI ( $r = .34, p < .001$ ). The permissive scale was correlated with the Laxness subscale of the PS ( $r = .26, p < .001$ ), the Over-reactivity subscale of the PS ( $r = .27, p < .001$ ), and the Limit Setting subscale of the PCRI ( $r = -.30, p < .001$ ).

The PAQ-R was also chosen because it has a number of helpful characteristics: it is quick and easy to complete; parents are not likely to be put off by complex questions that require support from others; it is designed for parents of children of all ages up to eighteen, since the questions are constructed to enable them to be interpreted in an age-appropriate way. The questionnaire is a genuinely 'service user friendly' instrument (Reitman, et al., 2002).

## **2.7 Socio-demographics and in-hospital setting factors**

The socio-demographic and in-hospital setting questionnaire (Appendix 10) comprised of questions on sociodemographic factors, which included the age, gender and ethnic origin of the child, the first language spoken by the child and by their parent, parent's gender and occupation.

As well as In-hospital setting factors, which included number of people accompanying the child to hospital, how many times the child had been admitted to hospital overnight before (quantity of admissions), whether previous hospital admissions were remembered as pleasant or unpleasant (quality of admissions), whether preparation was received on this occasion, time taken to travel from home, whether the child stayed in the night before, how long the child had waited for the procedure, how long the child had known that the procedure was going to take place, whether the child was expected to stay overnight after the procedure and whether the procedure was scheduled for the morning or afternoon. These data were used to investigate their impact on the child's preoperative anxiety and to ascertain the composition of the sample, as well as for comparison with other studies.

### 3 Procedure

Approximately four weeks before the child's scheduled surgery at the Evelina London Children's Hospital children and their parents are required to attend a preoperative assessment clinic (PAC).

Upon arrival to the PAC the specialist nurse or healthcare assistant informed potential participants (child and parents) about the study. The study invitation and information sheets (Appendix 11) and two children's information sheets, one for children aged 8 to 12 (Appendix 12) and one for children aged under 8 (Appendix 13), were given to parents to read. In this way parents were given the choice to decide which children's information sheet they thought was most appropriate for their child.

During the PAC appointment parents were asked for their permission to have their details passed to a researcher and to be approached by a researcher on the day of their child's surgery. They were informed that they did have to decide immediately to join the study and if they would prefer to take longer to think about this decision then they could contact a member of the research team at a later time. The care team also highlighted to potential participants that there was no obligation to take part in the study and non-participation would not have a negative effect on the way they (parents and child) would be treated at the hospital. They were also reassured that if they were to decide now that they would like to take part this would not be a problem.

The PAC care team recorded the details, including the time and date of the scheduled surgery, for potential participants who had agreed to have their details passed on to the research team. A researcher then collected this information from the PAC care team at the end of the clinic. All potential participants were given the information sheets to take home; including the contact details of the research team should they wish to ask any further questions about the study before the day of their child's procedure. For those eligible participants that did not make a decision at the PAC, they had the opportunity to contact the research team before their child's scheduled surgery to give their permission to be contacted by the research team.



On the day of the child's planned procedure all families are required to arrive on their designated ward at the Evelina London Children's Hospital at 7:00am. There is an all day theatre list on a Monday and as such the admission times are staggered throughout the morning, the first arrival time is 7:00am, and the last arrival time is at 11:00am. Upon arrival the children were admitted to the ward by the care team (nurses and health care assistants). Once admitted and settled into the ward a member of the research team then approached potential participants (who had agreed to be approached by the research team) and (re)informed them about the study. The information sheets were (re)given to the parents and, following any questions being answered, the consent (Appendix ) and assent forms (Appendix ) were then signed and dated, indicating that the parent and child had consented to take part in the study. A member of the research team then completed the sociodemographic data form with the parents and the in-hospital settings questionnaire. Parents were given the VAS-Proxy and VAS-Adult to complete. Parents were then given the CISS-SSC, the PAQ-R and the STAI and they were offered the choice to complete these remaining questionnaires either before or after their child was taken to theatre. Although it was felt these measures were not state dependent, and therefore, the timing of administration would not affect the result, this information was recorded and analysed. A member of the research team then supported the child (ages 7 and above) to complete the VAS-Child. Upon collecting the questionnaires from the parents the usual procedure prior to the administration of anaesthesia was carried out by the health care staff as normal. For those parents who decided to complete the questionnaires after their child went to theatre the remaining questionnaires were collected by a member of the research team from the parents on the ward later the same day.

One trainee Clinical Psychologist and two medical students (King's College London) taking an intercalating degree in psychology were involved in the data collection.

The ENT and cleft nursing teams were consulted in its design, in order to plan the study to fit in with the daily running of busy PAC's and pre-admission wards.

## 4 Data Analysis

### 4.1 Overview

All statistical analysis were carried out using SPSS for Windows (Version 20.0).

For categorical socio-demographic variables and in-hospital setting variables independent sample Mann Whitney U test and Kruskal-Wallis test analyses were used to investigate differences between the independent variables and children's preoperative anxiety (m-YPAS).

Correlational analyses were conducted to examine the relationships in measures of children's preoperative anxiety: relationship between parent proxy report (VAS-Proxy) and the m-YPAS, and between child's self-report (VAS-Child) and the m-YPAS, and child's self-report (VAS-Child) and parent proxy report (VAS-Proxy) of children's preoperative anxiety.

Simple linear regression analyses were carried out to predict the relationship between previous predictor variables (variables that have shown to predict children's preoperative anxiety in previous research) and the m-YPAS. Previous predictor variables included child's age, quantity of previous hospitalisations, quality of previous hospitalisations and parent's state anxiety (VAS-Adult).

Simple linear regression analyses were carried to predict the relationship between parent variables and the m-YPAS. Parent variables included parent's trait anxiety (STAI) parental coping style (CISS) and parenting style (PAQ-R).

Spearman's correlations were used to examine correlations between two variables and independent sample Mann Whitney U test and Kruskal-Wallis test analyses were used to compare two independent groups if the normal distribution assumption of the data was violated. Any significant parent variables and previous predictor variables were entered into multiple stepwise regression analyses to indicate whether the proposed explanatory variables contributed to a model of children's preoperative anxiety. Bootstrapping resampling was used as an appropriate approach to statistical inference

when distributional assumptions were not met to obtain more accurate standard errors, confidence intervals and p values (Good, 2005). Bootstrapping is a computer-intensive robust approach to statistical inference that uses the sample data as population and repeatedly draws new samples from it with replacement. The sampling distribution of a statistic is then constructed empirically by resampling from the sample which determines robust estimates of standard error, confidence intervals and p-values.

#### **4.2 Missing data**

A systematic approach was taken to deal with missing data. Missing items on the STAI were replaced with prorated scores (replacing the missing value by the mean of all available scores of the same case) as detailed in the description of the test (Spielberger et al., 1970). Missing items on the CISS (Endler and Parker, 1999) and the PAQ-R (Reitman, 2002) were dealt with in the same manner. The CISS, the STAI and the PAQ-R data were missing from 3 parents (3%) and were not replaced.

#### **4.3 Data Screening**

Data were screened for normality of distribution and outliers. Of particular interest was the dependent variable; the m-YPAS total score. The Kolmogorov-Smirnov test revealed that this variable was indeed not normally distributed; the m-YPAS scores  $D(86) = 0.24$ ,  $p < .0001$  deviated significantly from the normal distribution (see table 1). The possibility of transforming this variable was considered; however the distribution of the m-YPAS was positively skewed ( $S = 1.68$ ) (i.e. many children achieved the minimum score on the m-YPAS = 23) which did not allow a log (or similar) transformation which is commonly recommended for positively skewed data. Therefore, to exclude extreme scores would not have been satisfactory as data would have been lost. The decision was taken that it was not useful to exclude any outlying values due to the extent of the skew and concerns over the ability to generalise (Wright, 2003), as children in a real-world setting may have such a wide range of scores.

It is of note that the skewed distribution of the m-YPAS was expected due to the nature of preoperative anxiety, i.e. as most children do not experience extreme levels of preoperative anxiety the data should be positively skewed.

A number of independent variable measures were identified as significantly different from a normal distribution. Table 1 shows a summary of the distribution statistics for the main independent and dependent variables. Skew ranged from -0.64-1.68 and was significant for a number of measures. Kurtosis values ranged from -1.71-2.5 and was significant for a number of measures. Again, the decision was taken that it was not useful to transform these variables in order to perform parametric tests or to exclude any outlying values. Because non-parametric alternatives for multiple regressions are not available in standard software, regressions were performed using robust bootstrapping methods as appropriate, for measures which differed significantly from normal distribution.

**Table 1: Tests of normality (Kolmogorov-Smirnov (D), Skewness (S) and Kurtosis (K))** for measures of children's preoperative anxiety (m-YPAS), previous hospitalisations (quantity and quality), parent trait (STAI) and state (VAS-Adult) anxiety, parental coping style (CISS) and parenting style (PAQ-R).

	D (df=86)	Skew (S)	Kurtosis (K)
<b>m-YPAS</b>	<i>0.24, p=.000***</i>	<i>1.68 (.25)</i>	<i>2.5 (.50)</i>
<b>VAS-Child</b>	<i>0.14, p=.012*</i>	<i>0.87 (.32)</i>	<i>0.37 (.63)</i>
<b>VAS-Proxy</b>	<i>0.24, p=.000***</i>	<i>1.58 (.25)</i>	<i>1.77 (.50)</i>
<b>Quantity of previous hospitalisations</b>	<i>0.31, p=.000***</i>	<i>3.03 (.25)</i>	<i>12.71 (.50)</i>
<b>Quality of previous hospitalisations</b>	<i>0.27, p=.000***</i>	<i>0.03 (.25)</i>	<i>-1.71 (.50)</i>
<b>VAS-Adult</b>	<i>0.06, p=.200</i>	<i>-0.15 (.25)</i>	<i>-0.99 (.50)</i>
<b>STAI</b>	<i>0.09, p=.065</i>	<i>0.82 (.25)</i>	<i>0.52 (.50)</i>
<b>CISS</b> Task Emotion Avoidant	<i>0.13, p=.001**</i>	<i>-0.64 (.26)</i>	<i>0.23 (.51)</i>
	<i>0.13, p=.001**</i>	<i>0.54 (.26)</i>	<i>-0.42 (.51)</i>
	<i>0.10, p=.033**</i>	<i>0.07 (.26)</i>	<i>-0.26 (.51)</i>
<b>PAQ-R</b> Authoritative Authoritarian Permissive	<i>0.06, p=.023*</i>	<i>-0.34 (.26)</i>	<i>-0.43 (.51)</i>
	<i>0.10, p=.200</i>	<i>-0.49 (.26)</i>	<i>0.91 (.51)</i>
	<i>0.12, p=.004*</i>	<i>-0.40 (.26)</i>	<i>0.34 (.51)</i>

\*denotes  $p < .05$ , \*\* denotes  $p < .01$ , \*\*\* denotes  $p < .001$

df = degrees of freedom

## 5 Results

### 5.1 Brief description of participating sample

Children were aged between 3 and 12 years (mean = 5.53 years). 51 were female (51.2%), 49 were male (48.9%). As cited by their parents 45 children were 'White British or White Other' (50%), 21 were 'Black or Black British' (23.3%), 15 were 'Mixed' (16.7%), 5 were 'Asian or Asian British' (5.6%) and 4 were 'any other mixed background' (4.4%). 77 children were admitted for Ear Nose and Throat procedures (85.6%), 13 for Cleft Lip and Palate (14.4%). Of the 90 parents taking part 79 were female (87.8%), 11 were male (12.2%). 50 parents identified themselves as religious (55.6%), 30 identified themselves as atheists (33.3%) and the remaining 10 declined to disclose (11.1%). 72 parents reported English as their first language (80%). The majority of parents stated they were 'Professionals' (30%) and 'House Workers' (28.9%). Table 2 provides the complete frequency breakdown of participating sample characteristics.

Although no formal comparisons were made, the sample characteristics were representative of the population from which it was drawn, as the hospital at which the study was carried out was a tertiary referral centre, receiving referrals from all over the UK, particularly the large city in which it was situated. There was an even spread of ages and an approximately equivalent number of boys and girls in the sample. There were, however, more children admitted under ENT compared to Cleft specialties. This is because ENT procedures occurred more frequently for the age group being studied. The difference in sample size for each speciality will be held in mind when considering any relationships between specialty and level of children's preoperative anxiety.

**Table 2: Characteristics of participants studied to determine predictors of children's preoperative anxiety**

<b>Socio-demographic Factors</b>	<b>Frequency (%)</b>
<b>Age of child</b>	
<i>3-5 years</i>	<i>64 (71.7%)</i>
<i>6-12 years</i>	<i>36 (29.3%)</i>
<b>Child gender</b>	
<i>Female</i>	<i>44 (48.9%)</i>
<i>Male</i>	<i>46 (51.1%)</i>
<b>Parent gender</b>	
<i>Female</i>	<i>79 (87.8%)</i>
<i>Male</i>	<i>11 (12.2%)</i>
<b>Ethnicity</b>	
<i>White</i>	<i>45 (50%)</i>
<i>Mixed</i>	<i>15 (16.7%)</i>
<i>Asian</i>	<i>5 (5.6%)</i>
<i>Black</i>	<i>21 (23.3%)</i>
<i>Other</i>	<i>4 (4.4.%)</i>
<b>Religion Practised</b>	
<i>Yes</i>	<i>50 (55.6%)</i>
<i>No</i>	<i>30 (33.3%)</i>
<i>Not stated</i>	<i>10 (11.1%)</i>
<b>First language</b>	
<i>English</i>	<i>72 (80%)</i>
<i>Other</i>	<i>18 (20%)</i>
<b>Occupation</b>	
<i>House worker</i>	<i>26 (28.9%)</i>
<i>Professional</i>	<i>27 (30.0%)</i>
<i>Manager</i>	<i>11 (12.2%)</i>
<i>Others (workers etc)</i>	<i>26 (28.9%)</i>

## 5.2 Comparisons with non-participants

12 parents (11.8%) who were approached by the researchers did not wish to take part. Although parents were not obliged to give reasons why they did not want to take part in the study, some spontaneously did so. Two parents said that they were expecting to be called to theatre shortly and didn't want to be rushed. Three parents were sleeping and it was felt unethical to wake them. Three parents were unable to speak English adequately enough to understand the questionnaires. One parent said they thought that taking part in the study might upset their child. One parent said that they were feeling too anxious to take part. One parent did not want to fill in the STAI or the PAQ-

R in particular because they felt it would upset them to think about the items. Two parents declined because they didn't think the research would benefit them.

### 5.3 Hypothesis testing

#### Hypothesis 1

**The proportions of children and parents experiencing high levels of preoperative anxiety will be similar to rates found in previous studies.**

We aimed to establish whether incidence in the current sample replicated previously established rates of children and parents high levels of preoperative anxiety. A large number of studies in the literature of children's preoperative anxiety quote incidence rates of 40-70% (e.g. Kain et al., 1996; Koteniemi et al., 1997; Wollin et al., 2004, Blount, Bunke, Cohen & Forbes 2001; Maclaren et al., 2009). In our total sample (N=90), rates of children's preoperative 'extreme anxiety' (m-YPAS score >30) were 33.3% (N= 30). In our total sample (N=90), rates of parent's preoperative 'extreme anxiety' (VAS score >30) were 73.3% (N =66).

#### Hypothesis 2

**There will be a significant association between self-report, parent report and examiner observational measures of children's preoperative anxiety.**

We aimed to examine the agreement between child's (aged 7-12 years old) self-report (VAS-Child), parent proxy report (VAS-Proxy) and examiner observational (m-YPAS) measures of children's preoperative anxiety.

Non parametric Spearman's rho correlations were used to examine correlations between VAS-Child, VAS-Proxy and m-YPAS measures of children preoperative anxiety (see table 3). There was a significant positive relationship between the m-YPAS and VAS-Proxy measures of children's preoperative anxiety,  $r_s = .631, p = 0.000$ . VAS-Proxy was significantly correlated with VAS-Child,  $r_s = .367, p = 0.006$ . There was no significant relationship between m-YPAS and VAS-Child  $r_s = .235, p > 0.084$ .



**Table 3: Spearman correlation coefficient matrix among m-YPAS, VAS-Child, and VAS-Proxy measures of children's preoperative anxiety**

	m-YPAS (n)	VAS-Child (n)	VAS-Proxy (n)
m-YPAS	1 (90)	<b>.235</b> (26)	<b>.631<sup>**</sup></b> (90)
VAS-Child		1 (90)	<b>.367<sup>**</sup></b> (90)
VAS-Proxy			1 (26)

<sup>\*\*</sup> Correlation is significant at the 0.01 level (2-tailed)

### Hypothesis 3

**There will be a significant association between socio-demographic variables and children's preoperative anxiety. There will be a significant association between in-hospital setting variables and children's preoperative anxiety.**

### Summary statistics

The demographic factors have already been discussed in the sample characteristics section. In terms of in-hospital setting factors. The majority of children travelled under 30 minutes to get to the hospital (47.8%) fewer had between 30 minutes and an hour (27.8%) or longer than an hour (24.4%). Only 15 children stayed in hospital accommodation the night before the procedure, 75 did not. The majority of parents reported expecting to stay in hospital the night after the operation (48.9%), others reported expecting to go home the same day (26.7%) and some parents reported not knowing (24.4%). Some parents reported having waited for their child's surgery for over 4 months (41.1%). Fewer had reported waiting for less than a month (21.1%). The majority of parents reported that their child knew the operation was going to take place (83%) and the timings of when they told their children differed; the majority being told within the past week (36.7%). For a complete breakdown of the hospital setting factors see table 4.

**Table 4: Characteristics of in-hospital setting characteristics studied to determine predictors of children's preoperative anxiety**

In-hospital setting factors	Frequency
<b>Type of surgery</b>	
ENT	77 (85.6%)
CLEFT	13 (14.4%)
<b>Number of people accompanying child to hospital</b>	
1	34 (37.8%)
2	42 (46.7%)
3	13 (14.4%)
4+	1 (1.1%)
<b>Duration of travel</b>	
0-15	18 (20.0%)
15-30	25 (27.8%)
30-60	25 (27.8%)
60+	22 (24.4%)
<b>Theatre list</b>	
AM	57 (63.3%)
PM	31 (34.4%)
Don't Know	2 (2.2%)
<b>Overnight before</b>	
Yes	15 (16.7%)
No	75 (83.3%)
<b>Overnight after</b>	
Yes	44 (48.9%)
No	24 (26.7%)
Not sure	22 (24.4%)
<b>How long had the child waited for the procedure</b>	
1: 0-4 weeks	19 (21.1%)
2: 4-8 weeks	10 (11.1%)
3: 8-12 weeks	11 (12.2%)
4: 12-16 weeks	13 (14.4%)
5: 16 + weeks	37 (41.1%)
<b>How long had the child known he/she is having a</b>	
Not aware	7 (7.8%)
> 1 week	33 (36.7%)
2 – 4 week	13 (14.4%)
5-8 weeks	8 (8.9%)

9-12	13 (14.4%)
13-16 weeks	8(8.9%)
16 +	8 (8.9%)
<b>Amount of preparation received</b>	
None	12 (13.3%)
Self prep	48 (53.3%)
Nursing prep	63 (70%)
Other (psychologist/play therapist etc)	26 (28.8%)

### Tests of relationships between variables

Independent sample Mann Whitney U test (U) and Kruskal-Wallis test (H) analyses were used to investigate differences between sociodemographic and in-hospital setting variables and the m-YPAS (see table 5). No significances between groups were found.

**Table 5: Non-parametric test results between sociodemographic and in-hospital setting variables and the m-YPAS**

<b>Socio-demographic and in-hospital setting variables</b>	<b>Test statistic</b>
Gender of child	U = 851.50, p=.309
Parent Gender	U = 404.00, p=.694
Ethnicity	H = 5.81, p =.214
Religion Practised	U = 647.50, p =.286
First language	U = 721.00, p=.278
Occupation	H = 0.63, p=.729
Type of surgery	U = 457.50, p=.769
Number of people accompanied the child to hospital	H = 0.988, p=.804
Duration of travel	H = 1.07, p=.786
Theatre list	H = 4.873, p=.087
Overnight before	U = 535.00, p=.755
Overnight after	H = 2.96, p=.398
How long had the child waited for the procedure	H = 1.71, p=.888
How long had the child known that he/she is having a procedure	H = 16.59, p=.617
Amount of Preparation received	H = 1.72, p=.633

#### Hypothesis 4

**There will be a significant association between previous predictors of children's preoperative anxiety and children's preoperative anxiety.**

It is expected that there will be a positive relationship between parent's preoperative anxiety, quantity of previous hospitalisations, quality of previous hospitalisations predictors and children's preoperative anxiety. The effect of child's age on children's preoperative anxiety has been shown to be inconsistent therefore the direction of the effect of child's age on children's preoperative anxiety will be exploratory.

48 children had previously experienced an admission to hospital overnight before (previous hospitalisation) (53.3%), 42 children had not (46.6%). Of the 48 children who had experienced a previous hospitalisation 6 parents reported this as an 'unpleasant experience' (12.5%).

Table 6 displays the mean (with standard deviations) values for previous predictor variables: child's age, quantity of previous hospitalisations, quality of previous hospitalisations and parental state anxiety (VAS-Child scores), as these variables have variably impacted on children's preoperative anxiety in previous research. Median values (with interquartile ranges) are also presented to give an indication of the spread of the distribution of scores.

**Table 6: Descriptive statistics for previous predictor variables**

	Mean (SD)	Median (IQR)
Age of child	5.53 (2.60)	5.00 (5.00)
Quantity of previous hospitalisations	1.43 (2.37)	1.00 (2.00)
Quality of previous hospitalisations	1.42 (1.23)	2.00 (3.00)
VAS-Adult	49.42 (48.00)	29.23 (48.25)

SD = Standard deviation, IQR =Inter-quartile range

### Test of relationships between previous predictor variables

Simple linear regression analyses and correlational analyses were carried out to evaluate whether the following previous predictor variables predicted the m-YPAS scores in the current sample: child's age, quantity of previous hospitalisations, quality of previous hospitalisations and parental state anxiety (VAS-Adult scores). No significant regressions or correlations were obtained (see table 7). Table 7 also shows that the differences between the standard error of the betas for the previous predictors of children's preoperative anxiety in the original and the bootstrap sample (bias) were small. This finding suggests that the standard errors from the original regression analyses were reliable, and, thus, within this sample, the simple linear regression analyses seem robust.

**Table 7: Results of correlational and simple linear regression analyses between variables of previous predictors of preoperative anxiety and the m-YPAS**

	r	$\beta$ 95% CI <sup>a</sup>	SE <sup>a</sup>	t	P <sup>a</sup>	Bias (SE – SE bootstrapped)
Age of child	.182	-.002 to 1.232	.315	1.738	.052	.040
Quantity of previous hospitalisations	-.036	-.755 to .6544	.324	-0.341	.633	.071
Quality of previous hospitalisations	.214	-.364 to 5.174	1.501	1.576	.096	.108
VAS-Adult	.139	-.018 to .100	.032	1.320	.167	.002

<sup>a</sup> Based on 10000 bootstrap samples

CI = Confidence Interval, SE = Standard Error

### Hypothesis 5

**There will be a significant association between parent variables and children's preoperative anxiety:**

**There will be a significant association between parental coping style (CISS) and children's preoperative anxiety (m-YPAS).** It is expected that parents with a task-orientated coping style (CISS-task) will be related to lower preoperative anxiety (m-

YPAS) in their child compared to parents with an emotion-orientated (CISS-emotion) or avoidant coping style (CISS-avoidant) whose children will be more anxious (m-YPAS).

**There will be a significant association between parenting style (PAQ-R) and children's preoperative anxiety (m-YPAS).** It is expected that an 'authoritative' parenting style (PAQ-R authoritative) will be related to lower preoperative anxiety, whereas 'permissive' parenting (PAQ-R permissive) and 'authoritarian' (PAQ-authoritarian) parenting styles will be related to higher preoperative anxiety (m-YPAS).

**There will be a significant positive association between parent's trait anxiety (STAI) and children's preoperative anxiety (m-YPAS).**

### Summary statistics

Table 8 displays the mean (with standard deviations) values for the preoperative measures. Median values (with interquartile ranges) are also presented to give an indication of the spread of the distribution of scores.

**Table 8: Descriptive statistics for parent variables studied to determine predictors of children's preoperative anxiety**

Measure	Mean (SD)	Median (IQR)
<b>STAI</b>	37.05 (9.02)	36.00 (13.00)
<b>CISS</b> Task	22.93 (5.99)	23.00 (6.25)
	Emotion	13.76 (5.70)
	Avoidance	18.49 (4.80)
<b>PAQ-R</b> Authoritative	40.10 (4.98)	40.00 (5.00)
	Authoritarian	30.70 (5.93)
	Permissive	24.98 (4.96)

SD = Standard deviation, IQR =Inter-quartile range

### Test of relationships between parent predictor variables

Correlational analyses and simple linear regression equations were carried out to evaluate whether parent variables of children's preoperative anxiety predicted the m-YPAS scores in the current sample. Statistically significant regressions were obtained for two of the preoperative factors with the m-YPAS; CISS-avoidant  $t(86) = 2.172$   $p < .05$ ) and CISS-emotion  $t(86) = 2.699$   $p < .05$  (see table 9). For these data both

predictors have positive b-values indicating positive relationships. CISS-avoidant ( $b = .412$ ): this value indicates that as CISS-avoidant increases by 1 point, m-YPAS score increases by 0.412 and CISS-emotion ( $b = .435$ ): this value indicates that as a CISS-emotion increases by 1 point, m-YPAS score increases by 0.435.

Table 9 also shows that the differences between the standard error of the betas for the simple linear regression analyses in the original and the bootstrap sample (bias) were very small. This finding suggests that the standard errors from the original regression analyses were reliable.

**Table 9: Results of correlation and simple linear regression analyses between parent variables and the m-YPAS**

Measure	r	$\beta$ 95% CI <sup>a</sup>	SE B <sup>a</sup>	t	p <sup>a</sup>	Bias (SE – SE bootstrapped)
STAI	.094	-.136 to .323	.117	.889	.430	-.013
<b>CISS</b> Task Emotion Avoidance	.022	-.205 to .269	.121	.206	.788	.039
	.279	.090 to .767	.173	2.699	.017*	-.012
	.228	.044 to .775	.186	2.172	.029*	.004
<b>PAQ-R</b> Authoritative Authoritarian Permissive	-.150	-.618 to .048	.171	-1.390	.120	.022
	-.127	-.486 to .140	.160	-1.171	.238	.003
	.146	-.036 to .557	.150	1.349	.081	.044

\*denotes  $p < .05$ , \*\* denotes  $p < .01$ , \*\*\* denotes  $p < .001$

<sup>a</sup> Based on 10000 bootstrap samples

CI = Confidence Interval, SE = Standard Error

#### 5.4 Stepwise multiple regression analyses

Several multiple regression models were developed to determine the percentage of variance in m-YPAS scores that could be attributed to predictor variables and thereby to establish the independent risk factors for children's preoperative anxiety. In the first model 'previous predictor' variables: child's age, previous hospitalisations (quality and quantity) and parent state anxiety (VAS-Child) were included in the first step of the regression equation, as these variables have variably impacted on children's

preoperative anxiety in previous research. CISS-emotion and CISS-avoidant variables were included in the second step of the analysis, as these variables were found to be significant predictors based on the simple linear regression analyses.

### **m-YPAS score**

The  $R^2$  value for the first model was 0.151, indicating that the model accounts for 15.1% of the variance in m-YPAS score, but the predictive power of the model was not significant,  $F(1.332)=$ ,  $p=0.263$ . Backward model elimination was used to identify the best set of predictors.

Backward elimination removes the least important variable first, then after refitting the model, the next least important one, until no further improvement is possible.

Three further stepwise linear regressions were conducted; firstly we excluded the CISS avoidance but retained the CISS-emotion. Next, we excluded the quality but retained the quantity of previous hospital admissions. Finally we excluded the CISS avoidance and the quality of previous hospital admissions.

### **Risk factors for children's preoperative anxiety**

The best final model of risk factors for children's preoperative anxiety included child's age, quantity of admission times and VAS-Adult variables in the first step and CISS-emotion in the second step. The  $r^2$  value for the model was 0.137, indicating that the model accounts for 13.2% of the variance in m-YPAS score, and the model was significant,  $F(3.149)=$ ,  $p=0.015$ . Three variables entered into the model were identified as significant predictors of m-YPAS: child's age, VAS-Adult and CISS-emotion (see table 10).

Analyses utilising the bootstrap method 10,000 bootstrap samples were used confirmed the existence of independent risk factors for children's preoperative anxiety. Table 10 shows that the differences between the standard error of the betas for the regression model of risk factors for children's preoperative anxiety in the original and the bootstrap sample (bias) were very small. This finding suggests that the standard errors from the original regression analyses were reliable.



**Table 10: Final model of risk factors for children's preoperative anxiety following stepwise regression**

	B CI <sup>a</sup>	SE <sup>a</sup>	$\beta$	t	P <sup>a</sup>	Bias (SE – SE bootstrapped)
Step 1						
<b>(Constant)</b>	18.899-	2.204		7.860	.000	.723
<b>Childs age</b>	.207 - 1.373	.295	.237	2.196	.009**	.071
<b>Admission</b>	-.921-.49	.340	-.067	-.632	.402	.054
<b>VAS-Adult</b>	-.002-.116	.030	.191	1.800	.050*	.002
Step 2						
<b>(Constant)</b>	14.000-	2.325		5.590	.001	1.02
<b>Childs age</b>	.203-1.379	.297	.242	2.307	.006**	.059
<b>Admission</b>	-1.013-.367	.333	-.077	-.743	.313	.051
<b>VAS-Adult</b>	-.038-.091	.033	.089	.799	.418	.001
<b>Emotion (CISS)</b>	.025-.800	.201	.266	2.405	.042*	-.003

\*denotes  $p < .05$  \*\* denotes  $p < .01$ , \*\*\* denotes  $p < .001$ a.

Bootstrap results are based on 10000 bootstrap samples

For this model, Childs age,  $t(83)=2.196$ ,  $p < .01$ , VAS-Adult,  $t(83)=.058$ ,  $p < .05$  and CISS-emotion  $t(83)=2.405$ ,  $p < .05$ , are all significant predictors of m-YPAS scores. The effect sizes for child's age, VAS-Adult and CISS-emotion were 0.242, 0.089 and 0.266 respectively; indicating that in this sample 24.2%, 8.9% and 26.6% of the variance in m-YPAS scores in our sample. These results suggest that age and emotion are of similar relative strength and both variables show stronger relative effects than the VAS-Adult. All relationships were positive in direction, i.e. as the values in the independent variable increased, so did the values in the dependant variable. Childs age ( $b = .242$ ): this value indicates that as a child's age increases by 1 year, m-YPAS score increases by 0.242. VAS-Adult ( $b = .089$ ): this value indicates that as a parent's anxiety increases by 1 point, m-YPAS score increases by 0.089 and CISS-emotion ( $b = .266$ ): this value indicates that as CISS-emotion increases by 1 point, m-YPAS score increases by 0.266.

## 5.5 Qualitative Descriptives

### Parents views

Both mothers and fathers were given the opportunity to voice any other concerns they might have, as a part of completing the demographics form. The most commonly

voiced worries or concerns were the long wait “the longer the wait the worse the worries” (and associated hunger and thirst for the child). Many parents reported feeling “helpless” and “out of control” frequently stating not knowing how to help their child (with the boredom, hunger and postoperative side effects – i.e. pain and nausea) as sources of stress. One father reported feeling very anxious about his child being in pain after the surgery and reported feeling helpless to do “anything to make it better.”

Many parents described the impact of previous hospitalisations. A few parents spoke of their stress as a reflection of feelings and remembrances of past experiences. Some parents said that they found it easier to cope because they had previous experiences of their child having operations under general anaesthetic, which helped them know what to expect and cope with the worries better. One mother said that she had another child who had previously undergone a life threatening operation, which helped her ‘put things in perspective’ and cope today.

Three parents said that they found it easier to cope because they thought that the procedure was reasonably straightforward (tonsillectomy). However, one mother said they were more worried because they thought it was a complicated procedure (alveolar bone graft).

One father said “if she bleeds out I want to know more information about what would happen...so we are prepared for the worst.” One mother said that “I know they probably have to tell us by law, or something, but I would rather be given the information (about risks and side effects) to read myself, not be told about them.” One mother said that she would like a bit more information about the possible risks but also said that ‘there is a fine line between knowing too much and not enough.’

Two fathers said that the preparation received was biased towards the mothers. One father said that the information sheets only referred to mothers and another father said that they “did not feel included” in the preoperative conversations, believing the majority of the communication was aimed towards the mother. One Polish father

reported feeling anxious about possible health inequalities for ethnic minorities. He suggested that providing data showing evidence for equal treatment outcomes across different ethnic groups would help him to feel more settled.

One mother who was a member of an online forum for individuals with a cleft lip and palate and their families said that she had contacted a mother whose child had gone through the similar procedure. She said that talking to someone who had successfully been through it before helped her feel more prepared and confident about the operation. One Mum said that she took time off to go on holiday on her own before the scheduled surgery, which helped to reduce her general stress.

## 5.6 Section summary

Rates of 'high level' preoperative anxiety in children (m-YPAS score >30) were 33.3% and rates of 'high level' of parent's preoperative anxiety (VAS score >30) were 73.3% (N =66). Correlational analyses demonstrated that there was a significant relationship between children's observed anxiety (m-YPAS) and parent proxy report of children's preoperative anxiety (VAS-Proxy), and between children's self-reported anxiety (VAS-Child) and parent proxy report of children's preoperative anxiety. No significant relationships were found between sociodemographic factors and the m-YPAS, or in-hospital setting factors and the m-YPAS. Simple linear regression analyses showed parents' emotion focused coping style (CISS-emotion) and parents' avoidant focused coping style (CISS-avoidant) predicted higher scores on the m-YPAS. No significant relationships between previous predictors of children's preoperative anxiety and the m-YPAS. A multiple linear regression model revealed that child's age, parent's preoperative anxiety (VAS-Adult) and CISS-emotion predicted higher scores on the m-YPAS in the pre-operative period.

## 6 Discussion

### 6.1 Chapter summary

The chapter begins with a summary of the findings. Results are then considered in detail with respect to the existing literature. The limitations of the current study are reviewed, and theoretical and clinical implications of findings then discussed.

#### Summary of findings

The present study tested novel predictions regarding risk factors for children's preoperative anxiety. Our findings were mixed. Hypothesis one was not supported by the findings of this study, the proportions of children and parents experiencing high levels of preoperative anxiety were not similar to rates found in previous studies. Rates of children's preoperative anxiety were lower than those found in previous studies. However, rates of parent's preoperative anxiety were higher than those found in previous studies.

Hypothesis two was partly supported by the findings of this study. There was a significant correlation between children's observed anxiety (m-YPAS) and parent proxy report of children's preoperative anxiety (VAS-Proxy), and between children's self-reported anxiety (VAS-Child) and parent proxy report of children's preoperative anxiety. No significant correlation was found between children's observed anxiety and children's self-reported preoperative anxiety.

Hypothesis three was not supported by the findings, there were no significant between group differences between sociodemographic factors and the m-YPAS and between in-hospital setting factors and the m-YPAS.

Hypothesis four was partly supported as there was some evidence of significant relationships between established statistical predictors of children's preoperative anxiety and the m-YPAS; child's age and parent's preoperative anxiety (VAS-Adult) significantly predicted higher rates of children's preoperative anxiety, in our sample.

There were no significant relationships between other established statistical predictors of children's preoperative anxiety.

Hypothesis five was partly supported by the findings as there was some evidence of significant relationships between parent variables and the children's observed preoperative anxiety; parents' emotion focused coping style (CISS-emotion) significantly predicted higher rates of children's preoperative anxiety, in our sample. However, no significant predictors were found between the other parental factors and children's preoperative anxiety. A model for predicting the variance in children's preoperative anxiety was suggested by a multiple regression analysis, where child's age, parent's preoperative anxiety and parental emotion focused coping style were the significant factors.

These findings are now discussed in more detail in relation to the literature.

## 6.2 Hypothesis 1

**The proportions of children and parents experiencing high levels of preoperative anxiety will be similar to rates found in previous studies.**

### **Children's preoperative anxiety prevalence rates**

We found prevalence rates of children experiencing high levels of preoperative anxiety in the current sample to be lower than previous prevalence estimates in other samples. In our total sample (N=90), rates of 'high level' preoperative anxiety in children (m-YPAS score >30) were 33.3% (N= 30). Prevalence rates in our sample are lower compared to previous studies.

Reports of the prevalence of preoperative anxiety in children have varied over the years but in a review of the literature on preoperative anxiety incidence rates of high levels of preoperative anxiety are estimated at around of 40-70% of children (Litke et al., 2012), a range that is apparently consistent regardless of country, surgical procedure, or health care system (Bar-Mor, 1997). Most studies in the area of children's procedural distress reference incidence figures from Kain et al.,'s (1996) study. In this sample the authors assessed 163 children ages 2-10 years old and found

60% of children experienced 'extreme' anxiety (VAS score >30) in the holding area of the preoperative period.

There may be a number of explanations to why rates in the current sample are comparatively low. Firstly, the different rates may be partly accounted for by the measure used to assess preoperative anxiety levels. Early studies in the literature included global Likert-type rating scales of children's preoperative anxiety (Vernon et al., 1965, Visintainer and Wolfer, 1975). McCurty et al., (2011) argues that these tools often lack thorough validation, are not widely available, and details pertaining to their development are often unclear. According to Kain et al., (1996) likert rating scales are mainly designed to measure pain rather than anxiety. Therefore some studies may not have been using valid or reliable measures of preoperative anxiety and also may not be directly comparable to our study, which used the m-YPAS.

Secondly, the cut off score used to define 'high levels of anxiety' in the present study used m-YPAS >30 as suggested by Kain et al., (1997) who developed and validated the measure. Although the m-YPAS has been widely used, the cut-off scores used to define 'high levels of anxiety' varies. Kim et al., (2012) measured children's preoperative anxiety in 455 patients aged 2-12 years and found 54% of children experienced 'extreme' levels of preoperative anxiety. Li and Lam (2011) studied 112 children aged 7-12 years and found 46% of children in their sample experienced 'extreme levels' of preoperative anxiety. However these authors used the m-YPAS>40 as a cut-off for 'extreme' levels of preoperative anxiety and did not provide data for the prevalence rates of children who scored m-YPAS>30.

The current study was concerned with measuring preoperative anxiety in the 'holding area', which refers to the period from admission to the hospital until the patient is taken to theatre (RCN, 2013). This is a stress point frequently measured in the literature and prevalence rates compared here are with studies that assessed preoperative anxiety during this period. However, a third explanation for this

comparative difference in prevalence rates may be the time point in which we measured children's preoperative anxiety in the holding area. Power (2010) argues that the level of children's preoperative anxiety increases from admission until the induction of anaesthesia. In our study children's preoperative anxiety was measured shortly after admission and often before the child had been seen by the medical teams. It is possible that higher anxiety levels would have been observed in children if we measured children's preoperative anxiety immediately after they had been seen by the care team, or before they were taken to theatre.

Finally, the hospital in which this study was carried provides a number of preparation techniques to all children and their families coming for minimal stay surgery. All participants attended a preoperative clinic that provides the child with some exposure to the hospital environment, staff and information regarding their admission to hospital for surgery and include aspects of formal preparation (e.g. age appropriate preparation leaflets). The majority of studies investigating children's preoperative anxiety use convenient sampling methods therefore vary in the amount and quality of preoperative preparation participants receive. Some studies report that participants all participants attended a preoperative assessment clinics (e.g. Jjala et al., 2010) others report only some participants received preparation (e.g. Kain et al., 1996). There is a body of knowledge on preoperative techniques that has been shown to reduce preoperative anxiety in children undergoing surgery (e.g. McCann et al., 2001 and Vernon et al. 1993). Furthermore, it is possible that higher rates of children's preoperative anxiety shown in earlier studies may be reflective of the changes in the delivery of surgical services for children. There has been considerable change in the delivery of surgical services for children in over the past 20 years. Developments such as increased day surgery and more frequent day-of-surgery admissions as well as increased knowledge of the importance of preparation (Department of Health, 2010). Lower rates of children's preoperative anxiety in this study may be an artefact of modern surgery methods (for example, all children in this study were admitted on the day of their elective surgery) and better preparation techniques.

### **Parent's preoperative anxiety prevalence rates**

We found prevalence rates of parents experiencing high levels of preoperative anxiety in the current sample to be higher than previous prevalence estimates in other samples. In our total sample (N=90), rates of parent's preoperative 'high levels' of anxiety (VAS score >30) were 73.3% (N =66). Shirley et al., (1998) suggested that up to 42% of parents experience high anxiety around the time of their child's operation. Thompson et al., (1996) interviewed 100 parents before their child's surgery and identified 47% of parents as highly anxious (using the Leeds scale for self-assessment of anxiety). Kain et al., (2006) recruited 241 children aged 5 to 12 years and assessed child and parental preoperative anxiety levels and categorised 18% of parents into a 'high anxiety' group (as measured by a mean score  $44.8 \pm 11$  on the STAI state).

There may be a number of explanations for these different rates. To our knowledge there are three studies in the literature that report on the prevalence rate of parental preoperative anxiety and all three studies employed different measures to assess parent's preoperative anxiety (Thompson et al., 1996, Kain et al., 2006 and Shirley et al., 1998). Differences in prevalence rates of parental preoperative anxiety in this sample may also reflect changes in the delivery of surgical services. In this study all children were admitted for minimal stay surgery and were admitted on the day of the surgery. 48.9% of parents expected to stay the night, the remaining 51% were scheduled to go home the same day (although 24.4% of parents reported that they were unsure whether they would definitely be going). Although research has shown that minimal stay surgery has many advantages for patients as, crucially, it involves minimal disruption to lifestyle (e.g. Power et al., 2008). Other studies have highlighted that there is inadequate psychological support for parents, which has resulted in increased anxiety experienced by parents admitted for day surgery (e.g. Mitchell, 2012). In a study examining preparing children and family psychologically for day surgery, Mitchell (2012) revealed that most parents experienced difficulties in accepting the role of helping their children manage this stressful experience. Lee (2004) found that parents can feel pressurised by the assumption that they want to be



actively involved during anxiety provoking interventions. In this current study many parents in the qualitative data reported feeling “helpless” and “out of control” frequently stating not knowing how to help their child. Although purely speculative it is possible that with reduced admissions time, and therefore increased recovery time at home, parents may have to assume greater responsibility in the care of their children during the perioperative experience, which may have led to an increase in the prevalence rate of parent’s anxiety in this sample. However, due to a combination of limited data and different measures used for parental preoperative anxiety, these findings should be interpreted with caution.

### 6.3 Hypothesis 2

**There will be a significant association between self-report, parent report and examiner observational measures of children’s preoperative anxiety.**

We found significant correlation between parent proxy report of children’s preoperative anxiety (VAS-Proxy) ratings and children’s observed preoperative anxiety (m-YPAS) and significant correlation between children’s self-report (VAS-Child) ratings and parent proxy report of children’s preoperative anxiety. With respect to the accuracy of parent proxy report of children’s preoperative anxiety, there are very few studies in the literature that have examined this association, but some evidence that, in line with our findings, parents may be able to accurately assess children’s preoperative anxiety. McMurtry et al., (2011) found a moderate correlation between parents and children’s ratings of child anxiety during a venepuncture. Bringuier et al., (2009) found a significant correlation between the children’s self-report and the parents’ proxy report of children’s preoperative anxiety (Bringuier, 2009). Not all studies find significant correlations between child and parent reports (e.g. Nillison et al., 2012). There may be a number of explanations for these inconsistencies in findings. For example different measures used to assess anxiety (e.g. Nillison et al., 2012), timing of the assessment (e.g. McMurtry et al., 2011) and nature of the procedure (e.g. Bearden et al., 2011). Hence, findings may not be directly comparable to the results of our study. It has also been argued that that self-reports by proxy risk lack of validity

and reliability (Nillison et al., 2012 and Zhou et al., 2008). However, these findings add to a growing body of literature that implicate parents as accurate predictors of children's preoperative anxiety. This is an important finding, given that parents in collaboration with their children make the final decision regarding treatment of children's preoperative anxiety (i.e. whether the child is given sedative premedication)(Kain et al., 2006).

### **Child self-report**

No significant correlations were found between children's self-report and the m-YPAS. Again the literature in this area is mixed. Some studies have shown good correlation between child self-report and observer report of children's preoperative anxiety (e.g. Bringuier et al., 2009, McMurtry et al., 2011). Others have found no correlation (e.g. Chambers et al., 2005; Bearden et al., 2012).

We measured self-report in children aged 7 and above based on previous research that has demonstrated validity for the use of the VAS in children aged 7 years and above (Bringuier et al., 2009) and based on evidence that self-report measures assessing anxiety are unreliable for children below 7 years old (e.g. Huguet, McGrath & Pardos 2011; McMurtry et al., 2011). However one possible explanation may be that children aged 7-12 years are not consistently able to identify the affective and sensory aspects of the experience. It is also possible that child self-report and observer report measure different aspects of anxiety. Wright, Eisner, Stewart and Finley (2010) argue that it is possible that observers may not be able to observe all aspects of anxiety that are experienced internally.

Another explanation may be due to the limitation of the measure. A general observation is that the faces depicting high levels of anxiety are somewhat frightening in and of themselves. Although there is no evidence that the child's responses were impacted in this fashion, as they were not questioned about their feelings toward the faces, it is possible. Additionally, frightening faces may have been avoided by anxious children. Subsequent research should seek to examine the psychometric properties of

the VAS-Child with a larger sample. A larger sample would allow for better comparison across age groups and allow us to better examine any developmental effects in the measurement of child self-report of anxiety. These results may have also been affected by range restriction. Examination of the VAS-Child medians demonstrates that most children selected the first face (corresponding to a score of 0-10) despite this, the scores did range from 1 to 100 (the largest range possible). Subsequent research employing a larger sample size will allow this issue to be evaluated further. Newton and Buck (2000) argue that although pictorial scales represent a potentially useful means to measure anxiety in children, more studies are needed to determine their reliability and validity.

Whether children in this study were truly unable to identify anxiety or whether our measure was insufficient for the task remains unclear.

#### 6.4 Hypothesis 3

**There will be a significant association between socio-demographic variables and children's preoperative anxiety. There will be a significant association between in-hospital setting variables and children's preoperative anxiety.**

No significant differences between groups were found in the current sample. Few studies have reported on the influence of any parent or child demographics or in-hospital setting factors on children's preoperative anxiety. In partial support of the current findings Davidson (2006) found no effect of a child's gender on preoperative anxiety levels during induction of anaesthesia, which was consistent with the findings from Cagiran et al., (2014). Thompson et al., (1996) found no differences in children's preoperative anxiety based on procedure type. Wright et al., (2009) found that children's preoperative anxiety did not differ significantly as a function of gender, or type of surgery. Wollin et al., (2004) did not find any significant associations between child or parent's gender and children's preoperative anxiety. Nor did they find any significant associations between ethnicity, socioeconomic status, how many people accompanied the child to hospital and how long the child had known that he/she

would be coming to hospital and children's preoperative anxiety. This group did however find significant correlation between mothers who did not practice a religion with increased levels of children's preoperative anxiety.

It has been suggested that gender is linked to levels of preoperative anxiety in children. Mendez et al., (2001) found increased anxiety in girls, whereas Caladas et al., (2004) obtained an effect of increased anxiety in boys.

The lack of association in the current study may be due to lower anxiety scores measured shortly after admission and not closer to the induction. Another explanation may be the different measures employed by these studies to measure children's preoperative anxiety (e.g. Kain et al., 1996; Cagiran et al., 2014) or by the different time points during the preoperative period children's anxiety was measured (Caladas et al., 2004). Finally it is worth considering the homogeneity of the current sample. Although exploratory analysis shows that the participating sample is diverse (age, ethnicity, occupation), the sample size is not large enough to make any formal comparisons. Furthermore, few studies provide data on the sample characteristics and therefore it remains unclear whether these non significant findings may be an artefact of homogenous samples or whether sociodemographic factors and in-hospital setting factors affect children's anxiety. More research is needed with larger sample sizes and across different hospital settings. The majority of research into children's preoperative anxiety has been carried out in tertiary referral hospitals in large cities and uses opportunistic sampling methods. Therefore further studies are required across different types of hospitals and using truly heterogeneous samples to test this relationship.

## 6.5 Hypothesis 4

There will be a significant association between previous predictors of children's preoperative anxiety and children's preoperative anxiety. Based on previous research it is expected that there will be a significant positive association between parent's preoperative anxiety and quantity of previous hospitalisations and children's preoperative anxiety and a significant negative association between the quality of previous hospitalisations and children's preoperative anxiety. The effect of child's age on children's preoperative anxiety has been shown to be inconsistent therefore the direction of the effect of child's age on children's preoperative anxiety will be exploratory.

### Child's age

Using Simple linear regression analyses and correlational analyses to evaluate whether child's age predicted the m-YPAS scores in the current sample showed no significant predictors or correlations. The multiple regression analysis, however, demonstrated that child's age was a significant independent predictor for children's preoperative anxiety in this sample. The multiple regression model is significant and contains less residual variance than in simple regressions. Therefore, we can reliably conclude that a child's age is a significant, (although a small effect size  $\beta = .242$  (Cohen's (1988) criterion for a small effect ( $\beta = .14$ )), individual predictor of m-YPAS scores in the present study. This relationship was positive and therefore older age predicts high levels of preoperative anxiety.

There are mixed findings in the literature about the effect of child age in relation to children's preoperative anxiety. In partial support of this study's findings Kain et al., (1996) carried out a study looking at predictors for children's preoperative anxiety found that older children (aged 7 years and above) demonstrated higher levels of anxiety in the preoperative holding area (Kain et al., 1996). However, this study used a different measure for children's preoperative anxiety (VAS) and was carried out 18 years ago, therefore it is likely that surgical and preparation procedures have changed and hence, findings may not be directly comparable to the results of our study. Cagiran

et al., (2014) and Wright, Stewart and Finley (2013) found no association between children's age and their level of preoperative anxiety.

A number of studies found that younger age is associated with higher levels of children's preoperative anxiety (Kain et al. 2000 and Kain et al. 2006). Caldwell-Andrews et al., (2005) examined 289 children aged 2–12 years undergoing outpatient, elective surgery and general anaesthesia. Children's preoperative anxiety was assessed (using the m-YPAS) and they found younger (aged 2–6.9 years old) children were more anxious when compared with older children (aged 7–12 years old). Kim et al., (2012) investigated predictive factors for the requirement of preoperative sedation in 455 patients aged 2-12 years scheduled for surgery requiring general anaesthesia. The authors found that younger age (<6 years old) was one of the predictors for requirement for sedative premedication.

The lack of a stronger association in the current study may be due to lower anxiety scores measured shortly after admission and not on entrance to theatre or during induction of anaesthesia. The direction of age is not clear, more research needs to be carried out with larger sample sizes, with increased predictive factors such as parental coping style and investigating possible mediating factors. For example, Kain et al's., (1996) study found that children older than 6 years benefited from preparation. Although purely speculative, it is possible that the effect of age may be an artefact of preparation. Older children may have greater anxiety scores without preparation due to their greater ability to process cognitive information (Brewer et al., 2006). Overall, these findings add to a growing body of literature that implicate the importance of children's age on levels of preoperative anxiety and provides provisional evidence to support that children of different ages need to be prepared based on their developmental level.

### **Parent's state anxiety**

Using Simple linear regression analyses and correlational analyses to evaluate whether

parent's preoperative anxiety predicted the m-YPAS scores in the current sample no significant regressions or correlations were obtained. A multiple regression analysis, however, demonstrated that parent's anxiety was a significant independent predictor for children's preoperative anxiety in this sample. The multiple regression model was significant and contains less residual variance than in simple regressions. Therefore, we can reliably conclude that parent's preoperative anxiety is a significant individual predictor of children's preoperative anxiety in the present study. This relationship was positive and therefore high levels of parent's preoperative anxiety predict high levels of children's preoperative anxiety.

These findings are in line with a growing number of studies that have shown that parent's preoperative anxiety predicts children's preoperative anxiety (e.g., Davidson et al., 2006, Dreger & Tremback, 2010 & Cagiran et al., 2014,). Preoperative parental anxiety has been shown to lead to increased anxiety in children, not only during the preoperative period but also in the postoperative period (e.g. Kain et al., 1996 and Shirley et al., 1998). In terms of theoretical implications, broadly our findings supports the social learning theory hypothesis which claims that children learn from and model their behaviour and/or emotions on a parent or other model who exhibits desired behaviour/emotions. Kain et al., (2000) argue that parents can act as stress reducers for their children. Parents who are themselves more anxious in a given situation are less available to respond to their child's needs and his/her signals of increasing distress. Indeed, in these instances, a child's distress may further compound parental anxiety, thus rendering the parent increasingly less able to respond effectively.

It is of note that the predictive power of parent's preoperative anxiety may need to be interpreted with caution (see section 6.7 for a more detailed discussion).

#### **Quantity of Previous hospital admissions**

No significant regressions or correlations were obtained between previous quantity of admissions and the m-YPAS scores in the current sample.

Findings in the literature with regards to quantity of previous admissions are mixed. In support of our findings Katz et al., (1980) and Brophy and Erickson (1990) reported that previous surgery was not related to preoperative anxiety. However, Jay et al., (1983) found a negative correlation between the number of previous medical experiences and children's anxiety during bone marrow aspirations. Lumley et al., (1993) and Vetter (1993) reported that previous hospitalisation was a predictor for distressed behaviour post-operatively. There may be a number of explanations for these inconsistent findings. For example, these studies were carried out over 20 years ago and surgery and preparation procedures have changed, none of these studies used the m-YPAS to assess anxiety. Hence, findings may not be directly comparable to the results of our study.

One possible explanation why we did not find significant effect may be due to the overall limited number of previous admissions the children in our study experienced. The mean number of previous hospital admissions was 1.4, however, whilst the majority of children had either zero or one previous admission (73%), only 3 children in this study had more than 5 previous admissions. Davidson et al. (2006) recruited 1250 children aged 3-12 years and found that children with a history of more than five previous hospital admissions was a significant predictor of children's preoperative anxiety (measured using the m-YPAS)..

Although the children in this study attended a tertiary referral children's hospital, it would be expected that they would generally have had more previous procedures and hospital admissions. However, in this sample the majority of patients were under ENT specialty (85.6%) and of those 60.1% (n=51) were scheduled for tonsillectomy, which is the most common procedure for children in this age group (Powell & Wilson, 2012).

### **Quality of previous hospital admissions**

No significant regressions or correlations were obtained between quality of previous admissions and the m-YPAS scores in the current sample.



Few studies in the literature have investigated the effect of the quality of previous hospitalisations and children's preoperative anxiety. Kain et al., (1996, 2006) and Wollin et al., (2003) demonstrated that increased child's anxiety was significantly related to poor quality of previous medical experiences. However, in our current study only a limited proportion of participants experiences previous negative experience (n=6). Therefore our failure to find significant effects on previous admissions may be an artefact of the small sample size and hence reduced power to detect an effect. Hence these results must be interpreted with caution.

## 6.6 Hypothesis 5

**There will be a significant association between parent variables and children's preoperative anxiety:**

### **Parent's trait anxiety**

**It is expected that parents with a high trait anxiety will be significantly associated with higher levels of children's preoperative anxiety.**

No significant correlations or regressions were found between STAI and m-YPAS scores in the current sample. With respect to parents trait anxiety there is limited literature on its effect on children's preoperative anxiety. Kain (2006) examined parent's trait anxiety in relation to children's compliance during induction of anaesthesia and found a significant correlation between children's preoperative anxiety and parental trait anxiety (Kain et al., 2006). However, they measured anxiety at a different time point and therefore it cannot directly be compared to this study. Furthermore, most parents assessed in Kain et al., (2006) study were female (73%). In this current study the majority of parents assessed were also female (87%). Although there were no significant differences found between female and male trait anxiety scores, it is well evidenced that women consistently score higher than men on self-report measures of trait anxiety (see Egloff & Schmukle, 2004 for a review). A larger sample is needed to sufficiently power this analysis. Therefore results of these studies investigating parental trait anxiety must be interpreted with caution.

### **Parenting style**

**It is expected that authoritative parenting style will be significantly associated with lower levels of children's preoperative anxiety, whereas permissive parenting and authoritarian parenting styles will be associated with higher levels of preoperative child anxiety.**

No significant correlations or regressions were obtained between the PAQ-R and m-YPAS scores in the current sample. The results of this study did not provide support for the hypothesis that children's preoperative anxiety is influenced by parenting style. Brophy and Erikson (1990) also found that parenting style was not found to be related to children's preoperative anxiety. Carson et al., (1991) found that mothers who were more rejecting, overindulgent, and overprotective, had children who did not adjust well with hospitalisation (as measured by the p. However, these studies can be criticised because of major methodological limitations such a small sample sizes (Carson et al., 1991) inappropriate measures of parenting style (Brophy & Erikson, 1990) as well as homogenous samples (Carson et al., 1991).

Few conclusions can be made about the effect of parenting style due to the limited data, inadequate measures and their homogenous samples. It is possible that other samples of parents might show different results. More needs to be learned about the potential moderating role of parenting style on parents and children's preoperative anxiety.

### **Parental coping style**

**It is expected that parents with a task focused coping style will significantly associated with lower levels of children's preoperative anxiety and parents with an emotion-focused or avoidant focused coping style will be associated with higher levels of children's preoperative anxiety.**

A stepwise multiple regression model showed that parental emotion focused coping style (CISS-emotion) was a statistically significant individual predictor of the m-YPAS. In the simple regression analyses statistically significant regressions were obtained for

both parental emotion focused coping style (CISS-emotion) and parental avoidant focused coping style (CISS-avoidant) with children's preoperative anxiety (the m-YPAS). However, when both variables were combined into a multiple regression model, the CISS-avoidant was no longer a significant predictor variable whereas the CISS-emotion retained significance. It seemed that CISS-avoidant was an artefact of the overlap of CISS-emotion and the m-YPAS scores and was therefore excluded from the final best fit model. Therefore, we can reliably conclude that parental emotion focused coping style is a significant individual predictor of children's preoperative anxiety in the present study. This relationship was positive and therefore a higher level of parents' emotion focused coping style predicts higher levels of children's preoperative anxiety.

These findings are in line with a growing number of studies implicating the role of parental emotion focused type behaviour on children's anxiety. Chorney et al., (2009) found that overall, adult emotion focused behaviour such as empathy and reassurance significantly predicted an increase in children's anxiety and a reduction in children's coping behaviours at anaesthesia induction. Through correlational and experimental studies, a number of studies have shown parental emotion focused behaviour to be detrimental to children and related to increase in children's anxiety (e.g Blount, Landolf-Fritsche & Powers et al., 1991; Schechter, Zempsky, Cohen, McGrath, McMurtry & Bright, 2007). Evidence for the detrimental effects of reassurance has been provided in at least two experimental investigations (Chambers & Johnston, 2002; Manimala et al., 2000). These results are in line with Blount et al., (1989) suggestion that parents' emotion- focused behaviours focus children's attention on their own distress or on threatening aspects of the procedure, thereby heightening the children's anxiety. At the same time it is also possible that parents using more emotion focused coping are more focused on their own distress and therefore less able to respond to the needs of their children, thereby leading to an increase in children's anxiety.

Taken together these results add to a growing body of research suggesting the strong positive relation between adults' emotion-focused behaviours and children's anxiety.

## 6.7 Multiple regression

The results of the best fit multiple regression model indicate that child's age, parent's preoperative anxiety and parental coping contribute to individual variation in children's preoperative anxiety. In the first step of the multiple regression analysis, results revealed that older children ( $p = .009$ ) and higher levels of parent's preoperative anxiety (VAS-Adult) ( $p = .050$ ) are individual predictors for children's heightened preoperative anxiety. In the second step of the model, parental emotion focussed coping (CISS-emotion) was included and results showed that higher levels CISS-emotion ( $p = .042$ ) and older children ( $p = .006$ ) are individual predictors for children's heightened preoperative anxiety, whereas the VAS-Adult lost its predictive power ( $p = .418$ ). These findings suggest that CISS-emotion and VAS-Adult variables are measuring similar underlying or related concepts and therefore VAS-Adult is only significant if it is without CISS-emotion in the model.

Firstly, it is possible that the relationship between parent's preoperative anxiety and children's preoperative anxiety may be an artefact of parent's emotion focussed coping. This relationship was investigated and when the VAS-Adult was removed from the multiple regression analyses, CISS-emotion retained its effect and its predictive power increased ( $p = .008$ ). Endler and Parker (1990, 1999) showed similar results and found CISS-emotion positively correlated with adult's state anxiety. Although the CISS-emotion may be a better predictor of children's preoperative anxiety the results could also be due methodological limitations. It is possible that the findings could reflect the sensitivity of the measures. The CISS shows high validity and reliability (for a critical review see Rafnsson, Smari, Windle, Mears, A & Endler, 2006) compared to the VAS, which has been criticised for its psychometric properties (for a critical review see Wewers and Lowe, 1990). Secondly, reasons for the low reliability could be due to a smaller variation in the score of overall high rates of parent's preoperative anxiety (over 70% parents were highly anxious (vas score >30)) compared to CISS-emotion.

The relationship between the VAS-Adult and CISS-emotion is not clear and further research is needed to determine the underlying nature of this relationship. However,

the present study suggests that parental emotion focused coping and parent's preoperative anxiety, although they may be measuring something similar, are risk factors for children's preoperative anxiety.

The multiple regression model provides a structured explanation for the associations identified between potential influencing factors and children's preoperative anxiety. These results should be considered preliminary but provide valuable information for clinicians and researchers in terms of identifying parent-child dyads who may be at greater risk of experiencing heightened preoperative anxiety. It also confirmed a number of factors that have previously been identified as associated factors with children's preoperative anxiety. Crucially, information from this study can be used to inform assessment methods and identify children 'at risk' so that interventions for reducing preoperative anxiety can be efficiently targeted.

The results from this study are consistent with the theoretical framework stress and coping theory (Lazarus & Folkman, 1984) and confirmed that a variety of parent and child factors exist that influence how the parent-child dyad appraises the stress of hospitalisation for surgery as it unfolds instead of having trait coping strategies that pre-determine how they will cope. Results support the contextual nature of the stress of a child's hospitalisation for surgery which means that person and situation variables jointly shape coping efforts.

## **6.8 Limitations**

The current study has a number of limitations with regard to recruitment strategy, sample characteristics, and methodological factors. These are now discussed in turn.

### **Timing of m-YPAS**

A limitation of the current study is that preoperative anxiety was not measured during the most stressful times, i.e. on entrance to theatre and during induction of anaesthesia. It is possible that assessment of preoperative anxiety during these times may have altered the results in terms of the prevalence rate estimates of children's preoperative anxiety as well as the identification of more child, parent and in-hospital

factors associated with preoperative anxiety.

### **Follow up measures**

The current study did not measure any child or parent postoperative behaviours. Although previous studies show increased children's preoperative anxiety predicts adverse children's postoperative outcomes (e.g. Stargatt et al., 2006), measurement of outcomes following children's surgery and after their discharge from hospital would provide valuable information on the impact of children's preoperative anxiety over time in current UK surgical practices.

### **Generalisability**

Data collected in the current study were limited with regard to the child's surgery, i.e. specialty, complexity and length of procedure. These data could have identified specific factors related to the child's preoperative anxiety. During the development the ethics committee recommended excluding children whose parents could not speak English. This was because it was not possible to ensure that interpreters were available to these families. This obviously limits the ability to generalise the study to a general UK population and although very few families were not approached because of this exclusion criterion it remains that future work should consider this and aim to ensure access to inclusion in the study. A further exclusion criterion was that children undergoing life saving or emergency procedures were not to be approached. This was because it was felt that different concerns and levels of anxiety would be occurring for these families, further, it was deemed unethical to approach families at such a difficult time for them. However, one study has found that whether the procedure was elective or emergency made no difference to levels of preoperative anxiety (Holm-Knudsen, Carlin, & McKenzie, 1998). It may be possible, therefore, to generalise the findings of this study to children undergoing emergency procedures also.

### **Other predictors**

Although several factors in the preoperative period were selected to be included in this study following consultation with the literature and the studies aim, there may

have been other pertinent factors that were not included that could have had an effect on children's preoperative anxiety. It is possible that other child factors such as the child's locus of control (Bachanas & Roberts, 1995), child's temperament (e.g. Kain et al., 1996) and child's coping style (Blount et al., 1991) may have had an effect on children's preoperative anxiety levels. These child factors were not measured in this study for a number of reasons. First, it was felt that to include additional measures would be impractical to administer in a busy surgical ward. Second, extra questionnaires may have been overburdening for parents and their children. Furthermore it was decided that it was not within the scope of this project to comprehensively assess child predictors and, therefore, in line with the project's aim measures assessing parental factors were prioritised and investigated. Additional child and parent factors, along with many potential others related to the child's interactions with wider systems around them (for example, experiences at school) were not investigated in this study; however, further research is needed to examine the interaction between parent and child variables in the prediction of children's preoperative anxiety.

### **Measures**

The VAS-anxiety scales were used to measure children's self-reported anxiety, parent's state anxiety and parent proxy report of children's preoperative anxiety. As discussed previously in this section (see section 6.3.1 and 6.7), there may have been limitations in the measurement of anxiety.

Given the growing number of studies that have shown significant associations between parent and children's preoperative anxiety (e.g.) it is important to consider the impact of parental anxiety when administering the m-YPAS. In particular, the potential confound of the category 'use of parents' when measuring children's preoperative anxiety. Good concurrent validity between m-YPAS total score (using all five categories) and self-reported state anxiety assessed by the State Trait Anxiety Inventory for Children—State subscale (Spielberger 1973) in children aged 5–12 ( $r = 0.79$ ) has been demonstrated (Kain et al. 1997). Furthermore, in a study by Maclaren et al., (2009) the authors sought to assess the ability of anaesthesiologists, and

mothers to predict anxiety (using the m-YPAS) during induction of anaesthesia in 2 to 16-year-old children. They found that anaesthesiologist predictions were not significantly related to and mother trait (STAI-Trait) and state anxiety in holding (STAI-holding) (Maclaren et al., 2009). Although, these results suggest that parental anxiety was not a confound in assessing children's anxiety using the m-YPAS further research examining the concurrent validity of the m-YPAS, specifically the 'use of parents' category using a larger sample size is warranted.

### **6.9 Implications and directions for future research**

The immediate implication of this work for further study is to apply what has been learned here as described in the limitations section and to extend the study. Firstly, measuring children's preoperative anxiety just before the child is taken to the theatre in the preoperative period may show increased levels of anxiety. This information could provide evidence to support a greater number of risk factors for heightened preoperative anxiety and provide valuable information on targeting children at increased risk. Second, measurement of child and parent outcomes following children's surgery and after their discharge from hospital could provide valuable information for the planning and testing of interventions aimed at improving child and family outcomes following the child's admission to hospital for surgery. Comparing a greater number of children at different hospital sites, including equal number of male and female parent/carer participants, across a large number of specialties in truly homogenous sample, would enable generalisations from the work to be extended.

Future studies could investigate the validity and reliability of the VAS-anxiety scales in a larger sample of children and their parents across a broader age range. This approach may also shed further light on children's ability to observe and label anxiety and his/her willingness to respond honestly, as well as the relationship between parents' emotion focussed coping style and preoperative anxiety.

Parental emotion focused coping style was found to be a predictor of children's preoperative anxiety in this sample. Future investigation of parental emotion focused



coping style is needed to confirm these findings and further explore this relationship. It is recommended to include more items representing subtypes of coping and to include other potential mediating factors. Additional factors, such as locus of control and child's temperament (e.g. Kain et al., 2006) could be incorporated as possible mediating variables on the effect of parental coping on children's preoperative anxiety. Mediation analyses could be employed to identify and explicate the mechanism that underlies the relationship between parents emotion focussed coping and children's preoperative anxiety via the inclusion of a third explanatory variables (such as parent's locus of control).

Mediation analyses might be able to clarify the nature of the relationship between parental coping and children's preoperative anxiety (MacKinnon, 2008). Furthermore, many potential other predictors related to the child's interactions with wider systems around them (for example, experiences at school) could be incorporated in future work. Statistical methods such as sequential analyses could be applied to consider how interactions occur over time and can therefore comment on whether children's behaviours follow or precede adult behaviour (Chorney, Garcia, Berlin, Bakeman & Kain, 2010). For example, to enable examination similarity in parents' and children's coping styles or temperament may influence the degree to which parental behaviours facilitate or interfere with children's coping efforts and adjustment.

Although such extensions suggest a quantitative approach, a qualitative approach may also be an appropriate way to follow up the findings of this study. Parents could be interviewed to explore these factors further. A qualitative approach would allow richer data to be gained from the population and to explore the parents cognitions with regard to their coping, whether they are able to identify their particular coping style employed and whether the activities they engaged in for managing their child's surgery represents their 'typical' way of coping.

#### **6.10 Theoretical Implications**

The present study identified several risk factors for preoperative anxiety in children

undergoing surgery in the UK. Child's age, parent's situational anxiety and parental coping style have been demonstrated to be independent predictors of children's preoperative anxiety. The results from this study are consistent with the theoretical framework of stress and coping (Lazarus & Folkman, 1984) and confirmed that a variety of parent and child factors exist that influence how the parent-child dyad appraises the stress of hospitalisation for surgery. Cognitive appraisal and coping are two key processes in this theory that mediate how a stressful encounter relates to immediate and long term outcomes. The association between the significant predictors found in this study can all be described in terms of the parent/child's appraisal of the stressful event. Parents with emotion focused coping may blame themselves or become upset, which may lead them to become more self focused and less able to respond to their child's needs. Although older children may have the cognitive ability to appraise the situation, without formal preparation they may experience heightened anxiety due to their greater ability to process cognitive information. Lack of appropriate information or preparations would mean that the child may not have had the opportunity to learn adaptive coping skills and when the child is faced with the stressors of hospitalisation it may exacerbate the appraisal of the potential harmful aspects resulting in poorer coping. In the context of the theoretical framework child and parent anxiety are considered to be immediate outcomes of coping. Heightened child/parent anxiety are indicative of poor coping during the stressful event, which is either improved or worsened by additional factors that the dyad are exposed to prior to the child's surgery. The present study results support the contextual nature of the stress of a child's hospitalisation for surgery which means that person and situation variables jointly shape coping efforts.

Another important finding with theoretical connotations is that parent's preoperative anxiety predicts children's preoperative anxiety. This finding lends support to social learning theory that indicates that children learn behaviour from observing others. Parents can act as stress reducers for their children. Parents who are themselves more anxious in a given situation are less available to respond to their child's needs and

his/her signals of increasing distress. Indeed, in these instances, a child's distress may further compound parental anxiety, thus rendering the parent increasingly less able to respond effectively. A theoretical implication of the significant relationship between parent's and children's preoperative anxiety is the importance of parental factors in determining their child's ability to cope. Exploring both child and parent factors is essential in understanding how they influence child coping.

Given limited data investigating parental coping with children's preoperative anxiety further research is needed to replicate these findings. Nevertheless, some tentative theoretical implications will be discussed. The current study indicates that parents who used high levels of emotion focused coping predicts higher levels of children's preoperative anxiety. This finding also lends support to social learning theory (Bandura, 1977). In line with Chorney et al., (2009) suggestions that adults' emotion focused behaviours (reassurance, empathy, empathic touch) focus children's attention on their own distress or on threatening aspects of the procedure, thereby heightening the children's anxiety. Emotion focused behaviour may cue children to be distressed by communicating to the child that the situation should be of concern or may serve to direct attention toward the unpleasantness of the situation, thereby increasing distress.

The role of parental coping may be important to consider on several levels as parents may serve as resources to support and scaffold children's coping. Parents may serve as important models of effective and ineffective coping for their children, and parents' who use emotion focused coping with the stress of their child's hospitalisation, in turn may model this coping style for their children and may contribute to increased distress in their children.

In summary, stress and coping theory provides information about the possible mechanisms for decreased preoperative anxiety. Predictor variables can play a role in identifying patients who may be at increased risk of experiencing high levels of preoperative anxiety. Child's age, parental coping style and parent's anxiety can be

assessed and children at risk and their families can be targeted for preparation programs designed to promote coping and reduce preoperative anxiety.

### **6.11 Clinical Implications**

In sum, the current study examined children's anxiety in the preoperative period. Child and parental factors were identified that were related to increased children's preoperative anxiety.

#### **Preoperative Assessment Clinic (PAC)**

Following the results of this study and previous research, clinicians are able to inform parents regarding the possibility that their child will exhibit preoperative anxiety and the increased possibility they themselves will experience high levels of preoperative anxiety. Therapeutic techniques such as 'normalising' could be supported in delivering this information. Normalising is intended to communicate to parents that experiencing high levels of anxiety is not uncommon. Normalising is a well established principle in psychology has been shown to build trust, reduce anxiety and improve coping (Wolfensberger, 1980).

#### **Assessment**

Overall, our findings support previous studies that indicate specific factors that are important to consider when designing a preparation program (Kain & Andrews, 2005; Wollin et al., 2003). The results from this study acknowledge the importance of assessing parental coping, child's age and parent's preoperative anxiety as important predictors of children's preoperative anxiety and provide valuable information on targeting children at increased risk.

In theory these findings suggest that the CISS (Endler & Parker, 1999) represents a set of questionnaire items that may be useful in identifying children who may benefit from an anxiety-reducing intervention in the surgery context. Items from this subscale could be completed by the parent prior at the preoperative assessment clinic and scored on the day of surgery, yielding a score that could aid in determining if an intervention could facilitate anxiety reduction. However, it is likely that in busy surgical context this

method of assessing parental coping would be impractical. Previous research has shown that parents may be accurately able to identify their coping style in stressful situations (Bernard, Cohen, McClellan & MacLaren, 2004). Upon confirmation of these findings in the context of coping with children's surgery, parents could select the coping style that they believe most accurately reflects the activities they have engaged in before their child's operations. Those parents that identified themselves as emotion orientated could be identified for an anxiety reduction intervention.

These current findings support previous research that shows parents are able to accurately assess children's preoperative anxiety levels (Bringuier et al., 2009). The VAS-Proxy represents a single item scale that may be useful in identifying children who are experiencing high levels of preoperative anxiety. It is feasible that parents could complete the single item VAS-Proxy, which takes less than a minute to complete, during the nursing preoperative admission on the day of the surgery. Those children assessed as highly anxious (VAS score >30) could be identified for an anxiety reduction intervention.

### **Interventions**

High levels of preoperative anxiety have been identified as a risk factor for postoperative maladaptive behaviours such as separation anxiety, sleep and eating disturbances, and temper tantrums (e.g. Kain et al., 1996). These maladaptive behaviours may occur in up to 60% of children in the two weeks following surgery (Kain et al., 1996; Thomson & Vernon, 1993; Kontinemi et al., 1997). Also in line with our findings and previous research many parents report clinically significant increases in their own anxiety before their child's surgery, and that such increases in parental anxiety are associated with concomitant increases in the child's anxiety (Kain et al., 2003; Caldwell-Andrews et al., 2005; Cagiran et al., 2014). Preparing the child and his or her family for a surgical procedure has long been considered appropriate practice, and a number of studies have shown that adequate preoperative preparation can reduce preoperative anxiety for surgery, which leads to improved postoperative recovery (Kain et al., 2005).

These current findings provide support the assertion that interventions must target parents in addition to children (e.g. Kazak & Barakat, 1997) and that children who have been prepared with their parents report more satisfaction and show lower levels of anxiety (e.g. Jay & Elliot, 1990).

The present study results provide further evidence for the possibility of identifying children 'at risk' of heightened preoperative anxiety. This study supports the view that successful preoperative preparation is best achieved through comprehensive, age appropriate preparation of the child, as well as the parents, and has to utilise all suitable resources, personnel and strategies (Ahmed et al., 2011). Healthcare professionals taking care of children should recognise the risk factors, and individualise management of perioperative anxiety in a family-centred environment (Ahmed et al., 2011).

Power et al., (2012) suggests that parents need to be provided with appropriate information, services and support to enable them to care for their child during and after hospitalisation for surgery. Improving parent knowledge and enhancing parental coping will improve their self-efficacy regarding their ability to care for their child both in hospital and at home (Power et al., 2012). The National Service Framework (NSF) for Children advocates such care with the view that it will minimise stress for the family as a whole (DH, 2004). However, in line with this study and previous research it is important to ascertain the amount of involvement the family wish to have (Espezel & Canam 2003) and to provide an opportunity for the family to negotiate this (Corlett & Twycross 2006). Parents in this study expressed a multitude of different views about their child's surgery (see section 5.6.1 in the results). For example, regarding the need for information one mother in this study suggested that parents 'should be given the choice about how and when to receive the information' and another mother stated that 'there is a fine line between knowing too much and not enough.'

Ogilvie (1990) recommended more effective nursing care would be provided if nurses and other health care professionals had more knowledge of how the parents are

experiencing the hospitalisation and that the responsibility for psychological preparation of children cannot be fully shifted onto parents, as they may not manage, no matters how willing they are. In Melnyk, Crean, Feinstein and Fairbanks (2007) intervention study found that provision of parent role information could help reduce parent's preoperative anxiety and improve parents care for their child in hospital.

Although inconclusive, some data suggest that interventions congruent with an individual's coping style are more efficacious (e.g. Christiano & Russ, 1998). Sarafino (1990) stated that the benefits of psychological preparations for medical procedures seem to depend on the patients' coping styles, and it may be that different preparations are more helpful for people using avoidance strategies than for those using attention strategies (Sarafino, 1990). For preschoolers receiving immunisation injections, training parents (Blount et al., 1994) and nurses (Cohen et al., 1999) to distract children has yielded greater child coping and less distress. Evidence for the detrimental effects of reassurance has been provided in at least two experimental investigations (Chambers et al., 2002; Manimala, Blount & Cohen, 2000). Miller (1995) provided evidence to show that patients fare better (psychologically, behaviourally, and physiologically) when the information they receive about their medical condition is tailored to their own coping styles. Generally those who attend to and amplify threatening health information (monitoring style) tend to do better when given more information, whereas those who distract themselves from and minimise threatening health information (blunting style) do better with less information. However, patients with a monitoring style who are pessimistic about their future or who face long term, intensely threatening, and uncontrollable medical situations may require not just more information, but also, more emotional support to help them deal with their disease.

### 6.12 Summary

The findings were consistent with some of the hypotheses. Incidence rates of high levels of preoperative anxiety are estimated at around 40-70% of children (Litke et al., 2012) and 40% of parents (Shirley et al., 1998). However in contrast to hypotheses this study suggest that a lower proportion of children (33%) and a greater proportion of

parents (73%) experience high levels of anxiety before minimal stay surgery at a London Children's Hospital.

The finding that parent proxy report of children's preoperative anxiety is significantly correlated with children's observed preoperative anxiety is consistent with previous studies that implicate parents as accurate predictors of children's preoperative anxiety (McMurtry et al., 2011). Clinically, parents' accurate assessment of children's preoperative anxiety may aid healthcare providers in identifying children that may benefit from an anxiety reduction intervention. The discrepancy between children's self-report and children's observed report of preoperative anxiety supports further research into assessing the psychometric properties of the VAS-Child and into examining children's ability to observe and label anxiety.

The relationship between parental factors and children's preoperative anxiety were explored in greater detail in the current study than in previous research. Child's age, parent's situational anxiety and parents' emotion focussed coping style have been demonstrated to be independent predictors of children's preoperative anxiety. The results from this study are consistent with the theoretical framework of stress and coping (Lazarus & Folkman, 1984) and confirmed that a variety of parental and child factors exist that influence how the parent-child dyad appraises the stress of hospitalisation. This study appears to examine the relationship between parent, child and in hospital factors with children's preoperative anxiety in greater detail than in previous studies. Clinically, these findings support the possibility of identifying children 'at risk' of heightened preoperative anxiety and tailoring interventions to meet the specific needs of the parent-child dyad.

This study was cross sectional in design and had several limitations and replication is required. Whilst the findings have promising theoretical and clinical implications, whether they generalise to all parent-child dyads, the exact relationship between parental emotion focussed coping and children's preoperative anxiety is unclear and replication with other potential psychological moderators of effect is warranted.



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## 8 Appendix

### 8.1 Appendix 1: Conditional Letter of ethical approval



#### **Health Research Authority**

##### **NRES Committee London - Queen Square**

HRA Head Office  
Skipton House  
80 London Road  
London, SE1 6LH

Telephone: 020 7972 2556

16 May 2013

Miss Polly Crawford  
8 Lattimer Place  
Chiswick, W4 2UA

Dear Miss Crawford

<b>Study title:</b>	<b>Guiding intervention: Identifying parental psychological risk factors for pre-operative anxiety in children.</b>
<b>REC reference:</b>	<b>13/LO/0498</b>
<b>IRAS project ID:</b>	<b>122224</b>

Thank you for your letter of 14 May 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mr Thomas McQuillan, [thomas.mcquillan@nhs.net](mailto:thomas.mcquillan@nhs.net).

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### **Ethical review of research sites**

##### **NHS sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

##### **Non-NHS sites**

### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Information Sheet Children Aged Under 8 - Section 5 - Should read 'you AND your family'

Parents Letter should begin 'We ARE running ...'

Information Sheet for Parents - What are the risks and discomfort? - The following sentence "If you or your child finds it too distressing, you do not have to take part" could be written in a more sensitive and caring way.

If a carer/child finds something distressing, it is not enough to state that they do "not have to take part". They should also be offered care and support and the time to decide whether they wish to continue or not.

It is suggested that replacing the sentence above with the following (or something similar): "If you or your child finds it too distressing at any point, please let us know and we will stop the study immediately, until you are ready to continue. Remember that you do not have to take part and you are free to withdraw from the study at any time."

**You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.**

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

## 8.2 Appendix 2: Acknowledgement letter of the conditions for a full ethical approval



**NRES Committee London - Queen Square**  
HRA Head Office  
Skipton House  
80 London Road  
London, SE1 6LH

Telephone: 020 7972 2556

17 May 2013

Miss Polly Crawford  
8 Lattimer Place  
Chiswick, W4 2UA

Dear Miss Crawford

**Study title:** Guiding intervention: Identifying parental psychological risk factors for pre-operative anxiety in children.  
**REC reference:** 13/LO/0498  
**IRAS project ID:** 122224

Thank you for your e-mail of 17<sup>th</sup> May. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 16 May 2013

### Documents received

The documents received were as follows:

Document	Version	Date
Other: Letter to Parent/Guardian	5	14 May 2013
Participant Consent Form	5	14 May 2013
Participant Consent Form: Assent	5	14 May 2013
Participant Information Sheet: for Parents	5	14 May 2013
Participant Information Sheet: for Children Aged 8 - 12	5	14 May 2013
Participant Information Sheet: for Children Aged Under 8	5	14 May 2013

### Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Covering Letter		
Evidence of insurance or indemnity		20 July 2012
Investigator CV		15 March 2013
Letter of invitation to participant	3	15 March 2013

Other: CV: Dr Emma Godfrey	2	01 March 2013
Other: CV: Dr Jennifer A Cropper		
Other: CV: Dr Kate le Marechal		
Other: Email from Daniel Stahl re Power Analysis		
Other: Letter to Parent/Guardian	4	14 May 2013
Other: VAS-anxiety Parent Form	3	
Other: VAS-anxiety Parent Form	3	14 May 2013
Other: Letter to Parent/Guardian	5	14 May 2013
Participant Consent Form	5	14 May 2013
Participant Consent Form: Assent	5	14 May 2013
Participant Information Sheet: for Parents	5	14 May 2013
Participant Information Sheet: for Children Aged 8 - 12	5	14 May 2013
Participant Information Sheet: for Children Aged Under 8	5	14 May 2013
Protocol	4	15 March 2013
Questionnaire: The Modified Yale Preoperative Anxiety Scale		
Questionnaire: CISS: SSC		01 January 1999
Questionnaire: The PAQ-R		
Questionnaire: Self - Evaluation Questionnaire		
Questionnaire: Demographic Data		
Questionnaire: VAS - Anxiety Form		
REC application	122224/4254 87/1/4	05 March 2013
Response to Request for Further Information		14 May 2013

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

<b>13/LO/0498</b>	<b>Please quote this number on all correspondence</b>
-------------------	---

Yours sincerely



**Mr Thomas McQuillan**

**Assistant Committee Co-ordinator**

E-mail: NRESCCommittee.London-QueenSquare@nhs.net

Copy to: Ms Jenny Liebscher,  
Ms Karen Ignation, Guy's and St Thomas' NHS Foundation Trust

### **8.3 Appendix 2: Letter of Research and Development (R&D) approval**

**Guy's and St Thomas' NHS**  
NHS Foundation Trust

Research & Development  
16th Floor Tower Wing  
Guy's Hospital  
Great Maze Pond  
London SE1 9RT  
Tel: 020 7188 7188

Miss Polly Crawford  
Institute of Psychiatry  
Institute of Psychiatry, King's College London  
Addiction Sciences Building, 4 Windsor Walk  
London  
SE5 8AF

26/07/2013

Dear Miss Polly Crawford,

**Title:** Guiding intervention: Identifying parental psychological risk factors for children's pre-operative anxiety

In accordance with the Department of Health's Research Governance Framework for Health and Social Care, all research projects taking place within the Trust must receive a favourable opinion from an ethics committee and approval from the Department of Research and Development (R&D) prior to commencement.

- **Ethics Number:** 13/LO/0498
- **Sponsor:** IOP, KCL
- **Funder:** No external funding
- **End Date:** 30/06/2014
- **Protocol:** Version 4 (15<sup>th</sup> March 2013)
- **Site:** GSTFT
- **R&D Approval Date:** 26/07/2013
- **Chief Investigator:** Miss Polly Crawford

NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation as listed in the ethics letter of favourable opinion dated 17/05/2013. I am pleased to inform you that we are approving the work to proceed within Guy's and St Thomas' NHS Foundation Trust and that the study has been allocated the Trust R&D registration number **RJ113/N194** can confirm that from the SSI application form you have agreed to recruit 178 participants within 1 year.

Whilst the Trust takes on non funded research without charge for sponsorship, research management and governance or research costs we encourage all research to be funded and particularly encourage UKCRN portfolio eligible research. Prior to your next research proposal please contact the R&D department about portfolio eligibility and how to gain funding for research so as to ensure that the study can gain appropriate funding prior to your research application.

**Conditions of Approval:**

- The principal investigator must ensure that the recruitment figures are reported.
- The principal investigator must notify R&D of the actual end date of the project.
- R&D must be notified of any changes to the protocol prior to implementation.
- The project must follow the agreed protocol and be conducted in accordance with all Trust Policies and Procedures especially those relating to research and data management.
- Members of the research team must have appropriate substantive or honorary contracts with the Trust prior to the study commencing. Any additional researchers who join the study at a later stage must also hold a suitable contract.

**Data Protection:**

Please ensure that you are aware of your responsibilities in relation to The Data Protection Act 1998, NHS Confidentiality Code of Practice, NHS Caldicott Report and Caldicott Guardians, the Human Tissue Act 2004, Good Clinical Practice, the NHS Research Governance Framework for Health and Social Care, Second Edition April 2005 and any further legislation released during the time of this study.

The Principal Investigator is responsible for ensuring that Data Protection procedures are observed throughout the course of the project.

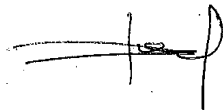
**Amendments:**

Please ensure that you submit a copy of any amendments made to this study to the R&D Department.

Should you require any further information please do not hesitate to contact us.

Thank you for registering your research project.

Yours sincerely



**Joanna Peel**  
**Research Facilitator**

cc: Dr Emma Godrey  
cc: Dr Jenny Cropper  
cc: Dr Kate LeMarechel



## 8.4 Appendix 3: The modified-Yale Preoperative Anxiety Scale (m-YPAS)

### The Modified Yale Preoperative Anxiety Scale

Please read each of the statements below and circle the number of whichever statement in each category applies to the child. Please do not tick more than one statement in each category.

#### Activity

1. Looking around, curious, playing with toys, reading (or other age appropriate behaviour); moves around holding area/treatment room to get toys or go to parent; may move toward operating room equipment
2. Not exploring or playing, may look down, fidget with hands, or suck thumb/blanket; may sit close to parent while waiting, or play has a definite manic quality
3. Moving from toy to parent in unfocussed manner, non-activity-derived movements; frenetic/frenzied movement or play; may push mask away or cling to parent
4. Actively trying to get away, pushes with feet and arms, may move whole body; in waiting room, running around unfocussed, not looking at toys, will not separate from parent, desperate clinging

#### Vocalisations

1. Reading (non vocalising appropriate to activity), asking questions, making comments, babbling, laughing, readily answers questions but may be generally quiet; child too young to talk in social situations or too engrossed in activity to respond
2. Responds to adults but whispers, "baby talk", only head nodding
3. Quiet, no sounds or responses to adult
4. Whimpering, moaning, groaning, silently crying
5. Crying, or may be screaming 'no'
6. Crying, screaming loudly, sustained

#### Emotional Expressivity

1. Manifestly happy, smiling or concentrating on play
2. Neutral, no visible expression on face
3. Worried (sad) or frightened, sad, worried or tearful eyes
4. Distressed, crying, extreme upset, may have wide eyes

#### State of Apparent Arousal

1. Alert, looks around occasionally, notices or watches what anaesthesiologist does (could be relaxed)
2. Withdrawn, sitting still and quiet, may be sucking on thumb or have face turned into adult
3. Vigilant, looking quickly all around, may startle to sounds, eyes wide, body tense
4. Panicked, whimpering, may be crying or pushing others away, turns away

#### Use of Parents

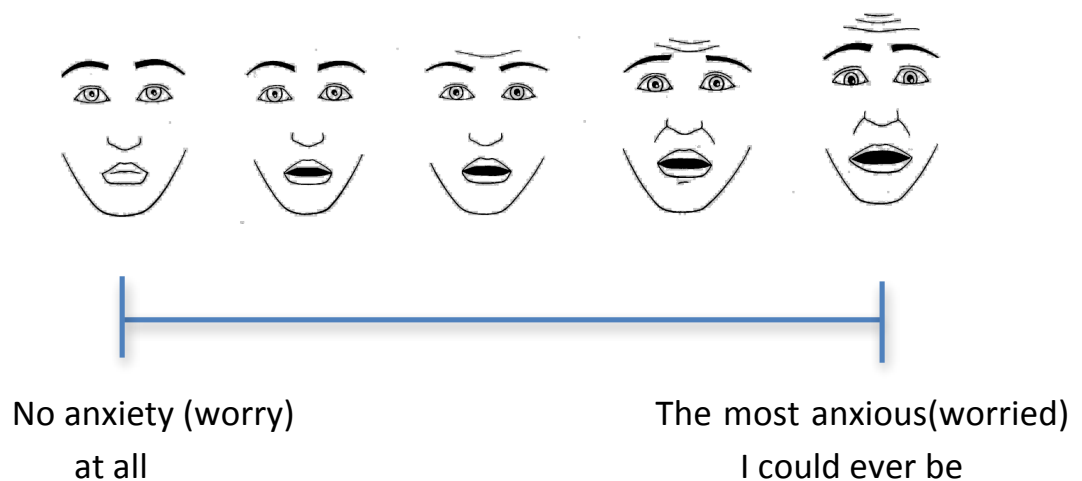
1. Busy playing, sitting idle, or engaged in age appropriate behaviour and doesn't need parent; may interact with parent if parent initiates the interaction
2. Reaches out to parent (approaches parent and speaks to otherwise silent parent), seeks and accepts comfort, may lean against parent
3. Looks to parent, apparently watches actions, doesn't seek contact or comfort, accepts it if offered or clings to parent
4. Keeps parent at a distance or may actively withdraw from parent, may push parent away or desperately clinging to parent and not let parent go

## 8.5 Appendix 4: The Visual Analogue Scale – Anxiety Self-Report (VAS-Child)

### VAS-anxiety Child Form

#### **Instructions for Children:**

“These faces are showing different amounts of being scared. This face (point to the left-most face) is not scared at all, this face is a little bit more scared (point to second face from left), a bit more scared (sweep finger along scale), right up to the most scared possible (point to the last face on the right). Have a look at these faces and mark an ‘X’ along the line to show how scared you feel now?”

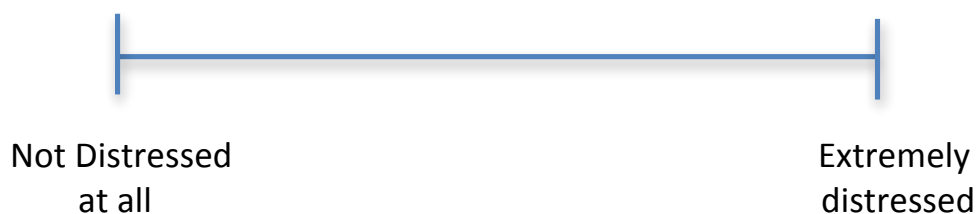


### 8.6 Appendix 5: The Visual Analogue Scale – Anxiety Parent Proxy Report (VAS-Proxy)

#### Instructions for Parents:

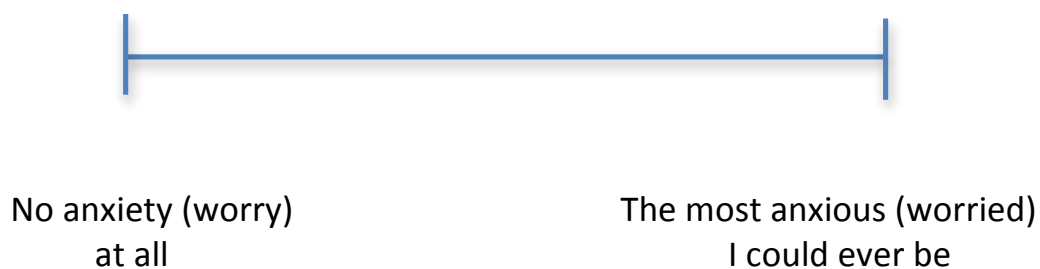
Please answer the following questions using the lines below. Please put a mark on the line so that it intersects. If you have any questions, feel free to ask.

Compared with same age children, how distressed does your child appear now?



### 8.7 Appendix 6: The Visual Analogue Scale – Anxiety Adult Self-report (VAS-Adult)

Please put a mark on the line to show how anxious (worried) you feel at the moment:



## 8.8 Appendix 7: The State-Trait Anxiety Inventory (STAI) trait subscale

**SELF-EVALUATION QUESTIONNAIRE**  
STAI Form Y-2

Name \_\_\_\_\_ Date \_\_\_\_\_

**DIRECTIONS.**

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you *generally* feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

	ALMOST NEVER	SOMETIMES	OFTEN	ALMOST ALWAYS
21. I feel pleasant .....	1	2	3	4
22. I feel nervous and restless .....	1	2	3	4
23. I feel satisfied with myself .....	1	2	3	4
24. I wish I could be as happy as others seem to be .....	1	2	3	4
25. I feel like a failure .....	1	2	3	4
26. I feel rested .....	1	2	3	4
27. I am "calm, cool, and collected" .....	1	2	3	4
28. I feel that difficulties are piling up so that I cannot overcome them .....	1	2	3	4
29. I worry too much over something that really doesn't matter .....	1	2	3	4
30. I am happy .....	1	2	3	4
31. I have disturbing thoughts .....	1	2	3	4
32. I lack self-confidence .....	1	2	3	4
33. I feel secure .....	1	2	3	4
34. I make decisions easily .....	1	2	3	4
35. I feel inadequate .....	1	2	3	4
36. I am content .....	1	2	3	4
37. Some unimportant thought runs through my mind and bothers me .....	1	2	3	4
38. I take disappointments so keenly that I can't put them out of my mind .....	1	2	3	4
39. I am a steady person .....	1	2	3	4
40. I get in a state of tension or turmoil as I think over my recent concerns and interests .....	1	2	3	4

## 8.9 Appendix 8: The CISS:SSC

CISS:SSC		by Norman S. Endler, Ph.D., F.R.S.C. & James D. A. Parker, Ph.D.				
Client ID: _____	Age: _____	Gender: M F	Date: ____/____/____			
Occupation: _____	Education: _____	Marital Status: _____				

**Instructions:** The following are ways people react to various difficult, stressful, or upsetting situations. Please circle a number from 1 to 5 for each item. Indicate how much you engaged in these types of activities **during this specific situation**.

This situation was \_\_\_\_\_  
(please complete).

	Not at All	1	2	3	4	Very Much
1. Take some time off and get away from the situation	1	2	3	4	5	
2. Focus on the problem and see how I can solve it	1	2	3	4	5	
3. Blame myself for having gotten into this situation	1	2	3	4	5	
4. Treat myself to a favorite food or snack	1	2	3	4	5	
5. Feel anxious about not being able to cope	1	2	3	4	5	
6. Think about how I solved similar problems	1	2	3	4	5	
7. Visit a friend	1	2	3	4	5	
8. Determine a course of action and follow it	1	2	3	4	5	
9. Buy myself something	1	2	3	4	5	
10. Blame myself for being too emotional about the situation	1	2	3	4	5	
11. Work to understand the situation	1	2	3	4	5	
12. Become very upset	1	2	3	4	5	
13. Take corrective action immediately	1	2	3	4	5	
14. Blame myself for not knowing what to do	1	2	3	4	5	
15. Spend time with a special person	1	2	3	4	5	
16. Think about the event and learn from my mistakes	1	2	3	4	5	
17. Wish that I could change what had happened or how I felt	1	2	3	4	5	
18. Go out for a snack or meal	1	2	3	4	5	
19. Analyze the problem before reacting	1	2	3	4	5	
20. Focus on my general inadequacies	1	2	3	4	5	
21. Phone a friend	1	2	3	4	5	

Not at All Very Much



Copyright © 1999, Multi-Health Systems Inc. All rights reserved. In the U.S.A., P.O. Box 950, North Tonawanda, NY 14120-0950, (800) 456-3003.  
In Canada, 3770 Victoria Park Ave., Toronto, ON M2H 3M6, (800) 268-6011. Internationally, +1-416-492-2627. Fax, +1-416-492-3343 or (888) 540-4484.

## 8.10 Appendix 9: The PAQ-R

Parent Name: \_\_\_\_\_ Child's name: \_\_\_\_\_ Child age: \_\_\_\_\_ Child Sex: male / female

**PAQ-R Instructions:** For each statement below circle the number that best describes your beliefs about parenting your child. There are no right or wrong answers. We are looking for your overall impression regarding each statement. In the right column, please **CIRCLE** your answer for each item: SA = Strongly Agree; A = Agree; N = Neither Agree nor Disagree; D = Disagree; SD = Strongly Disagree.

- |  |                 |
|--|-----------------|
| 1. In a well-run home children should have their way as often as parents do. ....  | 1. SA A N D SD  |
| 2. It is for my childrens' own good to require them to do what I think is right, even if they don't agree. ....  | 2. SA A N D SD  |
| 3. When I ask my children to do something, I expect it to be done immediately without questions. ....  | 3. SA A N D SD  |
| 4. Once family rules have been made, I discuss the reasons for the rules with my children. ....  | 4. SA A N D SD  |
| 5. I always encourage discussion when my children feel family rules and restrictions are unfair. ....  | 5. SA A N D SD  |
| 6. Children need to be free to make their own decisions about activities, even if this disagrees with what a parent might want to do. ....   | 6. SA A N D SD  |
| 7. I do not allow my children to question the decisions that I make. ....  | 7. SA A N D SD  |
| 8. I direct the activities and decisions of my children by talking with them and using rewards and punishments. ....   | 8. SA A N D SD  |
| 9. Other parents should use more force to get their children to behave. ....   | 9. SA A N D SD  |
| 10. My children do not need to obey rules simply because people in authority have told them to. ....   | 10. SA A N D SD |
| 11. My children know what I expect from them, but feel free to talk with me if they feel my expectations are unfair. ....  | 11. SA A N D SD |
| 12. Smart parents should teach their children early exactly who is the boss in the family. ....  | 12. SA A N D SD |
| 13. I usually don't set firm guidelines for my childrens' behavior. ....   | 13. SA A N D SD |
| 14. Most of the time I do what my children want when making family decisions. ....   | 14. SA A N D SD |
| 15. I tell my children what they should do, but I explain why I want them to do it. ....   | 15. SA A N D SD |
| 16. I get very upset if my children try to disagree with me. ....  | 16. SA A N D SD |
| 17. Most problems in society would be solved if parents would let their children choose their activities, make their own decisions, and follow their own desires when growing up. .... | 17. SA A N D SD |
| 18. I let my children know what behavior is expected and if they don't follow the rules they get punished. ....  | 18. SA A N D SD |
| 19. I allow my children to decide most things for themselves without a lot of help from me. ....   | 19. SA A N D SD |
| 20. I listen to my children when making decisions, but I do not decide something simply because my children want it. ....  | 20. SA A N D SD |
| 21. I do not think of myself as responsible for telling my children what to do. ....   | 21. SA A N D SD |
| 22. I have clear standards of behavior for my children, but I am willing to change these standards to meet the needs of the child. ....  | 22. SA A N D SD |
| 23. I expect my children to follow my directions, but I am always willing to listen to their concerns and discuss the rules with them. ....  | 23. SA A N D SD |
| 24. I allow my children to form their own opinions about family matters and let them make their own decisions about those matters. ....  | 24. SA A N D SD |
| 25. Most problems in society could be solved if parents were stricter when their children disobey. ....  | 25. SA A N D SD |
| 26. I often tell my children exactly what I want them to do and how I expect them to do it. ....   | 26. SA A N D SD |
| 27. I set firm guidelines for my children but am understanding when they disagree with me. ....  | 27. SA A N D SD |
| 28. I do not direct the behaviors, activities or desires of my children. ....  | 28. SA A N D SD |
| 29. My children know what I expect of them and do what is asked simply out of respect for my authority. ....   | 29. SA A N D SD |
| 30. If I make a decision that hurts my children, I am willing to admit that I made a mistake. ....   | 30. SA A N D SD |

### 8.11 Appendix 10: Sociodemographic and In-Hospital setting questions

#### Child factors

Age.....

Gender.....

First language spoken.....

Ethnicity – please tick

White

White British

White Irish

White other

Mixed

White and black Caribbean

White and black African

White and Asian

Other mixed

Asian or Asian British

Indian

Pakistani

Bangladesh

Other Asian

#### Parent factors

Gender.....

Occupation.....

First language spoken.....

Religion practised.....

#### Black or Black British

Black Caribbean

Black African

Other Black

#### Chinese or other ethnic group

Chinese

Other

1. What type of procedure is your child having today?.....
2. Is your child on the morning or afternoon list? .....
3. How many times has your child been admitted to hospital overnight before? .....
4. Whether previous hospital admissions were remembered as pleasant or unpleasant:1=unpleasant; 2=neutral; 3=pleasant.....
5. How long has it taken you to travel to the hospital today? .....
6. How many people have accompanied your child to hospital? .....
7. Did you stay in the hospital the night before the procedure? .....
8. For how long have you known your child is going to have the procedure?.....
9. For how long has your child known that the procedure is going to take place? .....
10. Has your child received any preparation for the procedure? Please include any sort of preparation, for example nurses, surgeon, psychologist, or play therapist whether provided by St Thomas', parents or someone else? .....
11. Are you expecting to stay overnight after the procedure?.....



## 8.12 Appendix 11: Study invitation and information sheets

Dear Parent/Guardian,

### Waiting for an operation – do children worry?

We are running a study looking at anxiety before an operation under general anaesthetic in children aged between 3 and 12 years.

We are keen to understand better how children feel before a planned operation. We are most interested in the things that affect how anxious (or worried) children feel.

In order to do this, we are asking the families of all children who are coming into Hospital for a planned operation under general anaesthetic if they would take part.

Before you and your child decide if you would be willing to take part, please read the information sheets enclosed with this letter. There are three; one for the parents, one for children aged between 8-12 years, and one for children aged less than 8 years. Please decide which sheet it would be most appropriate for your child to read/have read to them.

If you decide that you would not like to take part that is fine. It will not affect the way you or your child are treated at the hospital. If you decide now that you would like to take part, but change your mind later, that is also fine. Again, this will in no way affect how you or your child is treated at the hospital.

If you have any questions, please get in touch.

Yours faithfully,

Polly Crawford (Trainee Clinical Psychologist)

### **For all enquiries about the project please contact:**

Polly Crawford (Chief Investigator and trainee Clinical Psychologist)

Email: [polly.p.crawford@kcl.ac.uk](mailto:polly.p.crawford@kcl.ac.uk). Phone: 0207 848 0733

### **Other members of the research team:**

Dr Kate Le Maréchal (Lead Clinical Psychologist at South Thames Cleft Service - Guy's and St Thomas' NHS Foundation Trust)

Email: [kate.LeMarechal@gstt.nhs.uk](mailto:kate.LeMarechal@gstt.nhs.uk) Phone: 020 7188 1316

Dr Jenny Cropper (Clinical Psychologist, St Thomas' Hearing Implant Centre) Email: [jenny.cropper@gstt.nhs.uk](mailto:jenny.cropper@gstt.nhs.uk) Phone: 0207 188 9433

Dr Emma Godfrey (Lecturer in Psychology Departments of Psychology, Institute of Psychiatry, King's College London)

Email: [emma.l.godfrey@kcl.ac.uk](mailto:emma.l.godfrey@kcl.ac.uk) Phone: 020 7848 6332

## **Information Sheet for Parents**

### Waiting for an operation – do children worry?

You and your child are being invited to take part in a research study being conducted by research staff at the Institute of Psychiatry, King's College London. This study is being carried out at the Evelina Children's Hospital. The doctors taking care of your child have decided he/she needs to have an operation under general anaesthetic. We are currently doing a project looking at the levels of children's anxiety (or worry) before a procedure under general anaesthetic. We would like to ask your permission to include you and your child in this project. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please do not hesitate to contact us if there is anything that is not clear or if you would like more information. Please take your time to decide whether or not you wish to take part. Thank you for reading this.

### **The aim of the project**

The aim of this project is to try to measure children's levels of anxiety before an operation and to try to identify some of the factors that might affect this.

### **Why is the project being done?**

We know that some children feel more anxious (or worried) prior to the operation than other children. We hope that if we can understand better some of the reasons for this, a questionnaire could be used to check which children are most at risk. Children and their families could then be given extra preparation for the operation, which might help children feel less worried.

### **How will the project be done?**

If you agree to take part in the study, a researcher will come to see you whilst you and your child are waiting on the ward before the operation. The study asks only the main caregiver to take part. The researcher will ask you (the main caregiver) to answer some questions on a questionnaire about how you feel. This will take about 5 minutes. Your child will also be asked to answer one question about how they feel. This will take a few seconds. The researcher will complete a checklist to look at your child's level of anxiety (worry). This part will be done without your child needing to do anything. The researcher will not be alone with your child at any point during the study and the study will take place on the ward. After your child has been taken to the operating theatre you will then be asked to complete two more questionnaires. This will take about 10 minutes.

### **Why have I been invited to take part?**

You have been invited because your child is between 3 and 12 years and scheduled to have an operation under general anaesthetic

### **What will happen if I agree to take part?**

A member of the nursing care team will ask you at your pre-operative appointment whether you are interested in taking part in this project. If you are interested in taking part, then the care team will pass on your name to us (the research team). We will then talk to you in person about the project once you have been admitted to hospital, while you are waiting for your child to be called to the operating theatre.

If you agreed to take part in the study we will ask you a few questions and give you a few short questionnaires to complete. We will also ask your child a question about how worried he/she feels.

**What are the risks and discomfort?**

Some parents may find it upsetting to think about their child feeling anxious (or worried), and some children may find it upsetting to think about their worries. However, children and parents also find it helpful to talk about their worries. You will be asked to complete a questionnaire about different parenting styles and different ways of coping with stressful situations. Some parents may find some of the questions invasive and may cause some anxiety. We think it is important to ask you these questions so we can better understand which behaviours may help children to feel less anxious (worried). The project is being run by psychologists; we are all trained in supporting people who may be going through a difficult time. There will be a researcher (psychologist) present on the ward to talk to you about any concerns you have and support you while you take part. If you or your child finds it too distressing at any point, please let us know and we will stop the study immediately, until you are ready to continue. Remember that you do not have to take part and you are free to withdraw from the study at any time. This will not affect the care or attention you receive from the hospital staff.

**What are the potential benefits?**

Some parents and children find it helpful to talk about their worries and feelings before surgery, possibly better preparing the child for the operation. It may also provide you both with an activity to complete during the time you are waiting to go to the operating theatre. We also hope there will be benefits for children and families in the future. After we have finished this project we hope that we will be able to understand better which children might feel more worried and give them extra preparation before the day of their operation.

**Who will have access to the information you get?**

All information which is collected from the study will be kept strictly confidential. Neither you nor your child's name is on the questionnaires we will complete together. Questionnaires will be stored in locked filing cabinets that will only be accessible to the research team involved in this study. The requirements of the Data Protection Act will be complied with at all times. If you have any questions about data protection, please contact the Data Protection officer via the switchboard on 02071889433.

**What are the arrangements for compensation?**

This research project has been approved by Queens Square Ethics Committee who believe that it is of minimal risk to your child. However, research can carry unforeseen risks and we want you to be informed of your rights in the unlikely event that any harm should occur as a result of taking part. No special compensation arrangements have been made for this project but you have the right to claim damages in a court of law. This will require you to prove a fault on the part of the researchers.

**Do I have to take part in this project?**

No. If you decide not to take part in this project, this is entirely your right and will not in any way affect your child's present or future treatment.

**Who is organising and funding the project?**

This is a joint project between Guy's and St Thomas' Hospital and King's College London. It has received no special funding.

**Who do I speak to if I have further questions or worries?**

A member of the pre-operative assessment care team will talk to you about this study at your appointment today and will give you the opportunity to ask any questions you may have. If they are unable to answer your questions then please contact Polly Crawford the Chief Investigator of the study (see contact details below).

If you have any complaints about the way in which the project is being or has been conducted, in the first instance please discuss them with one of the researchers. The researchers are Ms Polly Crawford, Dr Jenny Cropper, Dr Kate Le Maréchal, and Dr Emma Godfrey. If the problems are not resolved, or you wish to comment in any other way please contact the Chairman of the Research Ethics Committee by post via The Institute of Psychiatry, Denmark Hill, SE5 8AF or, if urgent, by telephone on 020 7848 3871, and the Secretary to the Ethics Committee will put you in touch.

**If you decide to take part you are still free to withdraw at any time without giving a reason. This will not affect the standard of care you and your child receive.**

**Contact for Further Information:**

Polly Crawford (Chief Investigator and Trainee Clinical Psychologist)

Email: [polly.p.crawford@kcl.ac.uk](mailto:polly.p.crawford@kcl.ac.uk). Phone: 0207 848 0733

**Other members of the research team:**

Dr Kate Le Maréchal (Lead Clinical Psychologist at South Thames Cleft Service - Guy's and St Thomas' NHS Foundation Trust)

Email: [kate.LeMarechal@gstt.nhs.uk](mailto:kate.LeMarechal@gstt.nhs.uk) Phone: 020 7188 1316

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Email: [jenny.cropper@gstt.nhs.uk](mailto:jenny.cropper@gstt.nhs.uk) Phone: 0207 188 9433

Dr Emma Godfrey (Lecturer in Psychology, Department of Psychology, Institute of Psychiatry, King's College, London)

Email: [emma.l.godfrey@kcl.ac.uk](mailto:emma.l.godfrey@kcl.ac.uk) Phone: 020 7848 6332

## **Information Sheet for Children Aged 8-12**

### Waiting for an operation – do children worry?

You have come/are coming to hospital to have an operation. We are interested in knowing how children feel before having an operation. Therefore, we would like to ask you and your grown-up to answer some questions about how you are feeling. There are not any right or wrong answers to these questions, they are just about how you feel. Whilst you are waiting for your operation we would like to see what you do and make some notes to help us understand how people behave before operations.

Take time to decide if you want to say YES or NO to our giving you the questionnaires and seeing you on the ward. Please read, or have someone read this information to you. Do not worry if you don't understand it straight away. A grown-up with you has also been told about this, and you can ask them to help you understand.

#### **1) Who are we and why are we doing this?**

This project is being run by psychologists. Psychologists are people who work in the hospital and who try to help to understand how children think and feel. We try to help when children and their families are having a difficult time.

We want to find out how children feel before having an operation. We also want to see if we can find out why some children are more worried than others. If we can find this out we might be able to help children in the future when they come for an operation like you. If we find out you need help, we will try and think of ways to make it easier for you on the ward.

#### **2) How will this change my stay in hospital?**

When you are already in the hospital, we will ask you a question about how you feel. This will only take a few seconds. We will also ask the grown-up with you to answer some questions. This will take about five minutes. This will take place on the ward with your family. You will not need to leave your family, or be alone. Nothing else will be different for you.

#### **3) Why do we ask you?**

We are asking children who are coming to the Evelina Children's Hospital for a planned operation.

#### **4) Do I have to take part?**

No. It is up to you and your family to decide. If you decide you don't want to, that's absolutely fine. The doctors and nurses will look after you in the same way and saying 'No' will not make any difference.

**5) What will you ask me to do?**

When you are already at the hospital, we will ask you and the grown-up with you to answer some questions.

**6) Is it dangerous?**

These are not difficult but some of the questions will be asking about your worries. Some children might find this upsetting.

**7) Will it help me and other children like me?**

You might find it helpful to talk about how you feel about having an operation.

Once we have finished the project, it will be easier to know which children in future might be worried, and so it will be easier to help them before the day of their operation.

**8) Who will find out what I say?**

Only the psychologists working on the project will know what answers you give. If we think that you are upset, we will tell the ward staff, but only if that is OK with you.

**9) Who can I speak to if I have any questions?**

You can speak to your family who have also been given information about this project. You can also speak to the doctors or nurses on the ward.

The psychologists involved in this research are Polly Crawford, Jenny Cropper, Kate Le Maréchal and Emma Godfrey. You and your family can always speak to one of them if you have any more questions. Your family also have the phone numbers of people to speak to if they have any complaints or worries.

Waiting for an operation – do children worry?

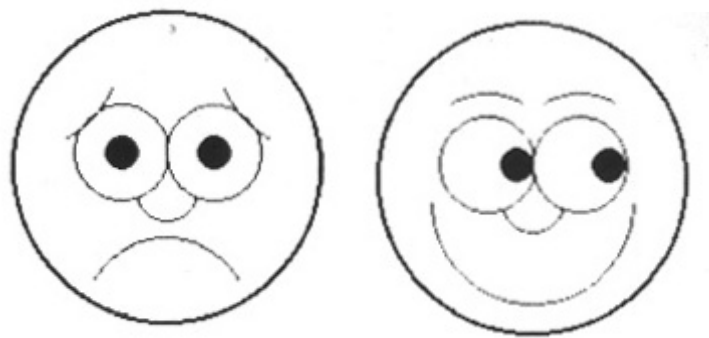
You have come/are coming to hospital to have an operation.

We want to find out how you feel about this. We would like to ask you and a grown-up with you to answer some questions before your operation. We would like to watch and see how you get on before your operation.

Think about whether you want to say YES or NO to this. Please read this information, or ask someone to read it to you. Don't worry if you don't understand straight away. We have told your family about this too, and they can help you understand.

**1) Why are we doing this?**

We want to find out how children feel before having an operation. We are also trying to work out which children worry about this. If we work this out, we might be able to help these children feel happier.



**2) Who are we?**

We are called psychologists. Psychologists are people who work in the hospital and who try to help to understand how children think and feel. We try to help when children and their families are having a difficult time

**3) What will be different for you?**

When you are already in the hospital, we will ask you a question about how you feel. This will only take a few seconds. We will also ask a grown-up with you to answer some questions. This will take about five minutes. This will take place on the ward with your family. You will not need to leave your family, or be alone. Nothing else will be different for you.



#### **4) Why do we ask you?**

We are asking children who are having an operation at the Evelina Children's Hospital to take part.

#### **5) Do I have to take part?**

No. It is up to you and your family to decide. If you say no, that is fine. The doctors and nurses will still look after you in the same way.

#### **6) What will you ask me to do?**

When you are already at the hospital, we will ask you the grown-up with you to answer some questions.

#### **7) Is it dangerous?**



These are not difficult but some of the questions will be asking about your worries. Some children might find this upsetting.

**8) Will it help me and other children like me?**

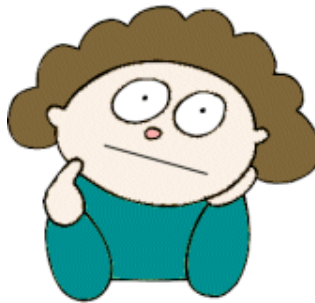
When we have spoken to lots of children, in future it might be easier to know which children will feel worried about having an operation. This would make it easier for us to help them.

**9) Who will know about what I say?**

Only the people who ask the questions to a grown-up with you will know what you say.

**10) Who can I speak to if I have any questions?**

You can speak your family who have also been given information about this project. You can also speak to the doctors or nurses on the ward.



The psychologists involved in this research are Polly Crawford, Jenny Cropper, Kate Le Maréchal and Emma Godfrey. You and your family can always speak to one of them if you have any more questions. Your family also have the phone numbers of people to speak to if they have any complaints or worries.

### 8.13 Appendix 12: Consent form

#### Consent Form

Participant identification number:

#### Waiting for an operation – do children worry?

Consent form to be signed by the parent or guardian of the child who will have an operation under general anaesthetic at St Thomas' Hospital.

1. I have read the information sheet about the above project and have had the opportunity to ask questions about the project and have had them answered. ☐
2. I agree that my child and myself can take part in the project as described in the information sheet. ☐
3. I understand that my consent is entirely voluntary and can be withdrawn at any time, without giving a reason, and that if I should do this, it will not in any way affect the way I and my child are treated at the hospital. ☐

**Name of Child**.....

.....	.....	.....
<b>Name of person giving consent</b>	<b>Date</b>	<b>Signature</b>

.....	.....	.....
<b>Name of researcher/ psychologist</b>	<b>Date</b>	<b>Signature</b>

#### 8.14 Appendix 13: Children's assent form

Children's assent form

Participant identification number:

##### **Waiting for an operation – do children worry?**

Assent form to be signed by the child who will have an operation at St Thomas' Hospital.

Please tick the boxes, if you agree and the answer is 'yes':

1. I have read the information sheet about the above project and someone has explained it to me and answered my questions.

☐

2. I know that I can change my mind about joining in anytime and I don't have to say why.

☐

3. I want to join in with the project

☐

If any answers are 'no' or you don't want to join in, don't write your name. If you do want to join in, write your name on the line.

**Childs Name**

.....

**Date:** .....

.....  
**Name of psychologist**

.....  
**Signature**

Service Evaluation Project

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## Developing a Social Skills Group within the Adoption and Fostering Team

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Project Supervisor: Dr Matt Woolgar

Clinical Supervisor: Dr Anouk Houdijk

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## Abstract

The research reported here examines the feasibility of recruitment and retention of a newly developed social skills intervention group for adopted and looked after young people showing subtle social skills problems. Targeted skills included conversational skills, developing friendship networks, good sportsmanship, changing bad reputations, and handling teasing, bullying, and arguments.

Quantitative and qualitative analysis revealed that treatment completers (n=4) reported very high satisfaction and improved knowledge of social skills. A low number of young people were recruited and completed the intervention. Due to poor return rate of questionnaires, there was an absence of parent and teacher informant data on young person's social skills improvement.

These findings highlight the importance of piloting different methods of administering and collecting measures. Face-to-face administration of measures for young people provides preliminary support for the acceptability of this method and future piloting is required to provide further evidence for the efficacy of collecting measures from young people in this way. Strategies to increase recruitment rates and response to questionnaires are discussed. Future piloting requires a larger number of participants and should provide other informant reports and follow-up data to be able to assess the efficacy of this treatment.

## 1 Introduction

### 1.1 Profile of Adopted Children and Looked After Children

The term 'looked after children' is a legal construct arising initially from the Children Act (1989) and refers to all children and young people being looked after by the local authority, including those subject to a compulsory care order and those looked after on a voluntary basis through an agreement with their parents (Children Act, 1989). The most up to date figures released by the Department for Education (2010) indicate that approximately 64,400 young people are currently looked after in England alone. The numbers of children being approved by the courts for adoption each year has risen from just over 3,000 in 2009-10 to over 4,200 in 2011-12. But in the same period the numbers of children moving in with adoptive families each year has risen much more slowly from 3,100 to 3,500. As a result, at the end of March 2012 there were over 4,600 children waiting to be able to move in with a new family.

### 1.2 The mental health of Adopted Children and Looked After Children

It is well established that young people looked after by the local authority have high prevalence rates of mental health difficulties (Meltzer, Corbin, Gatward, Goodman & Ford 2003; Richardson & Lelliott, 2003) and that their outcomes remain considerably worse than those of their peers (DCSF, 2009). There have been numerous research studies which have highlighted these findings; some have measured wellbeing at the point of entry into care (Dimigen, Del Priore, Butler, Ferguson & Swan 1999; Sempik, Ward, & Darker, 2008), whereas others have considered young people who had been looked after for some time (McCann et al., 1996) or referred to specialist services (Blower, Addo, Hodgson, Lamington & Towlson, 2004). The Office for National Statistics (ONS) indicate that 45% of the looked after population could be diagnosed with at least one psychiatric diagnosis, rising to 72% for those in residential care (Meltzer et al., 2003) in comparison to around 10% of the overall British population of young people (Meltzer et al., 2003). Clinically significant conduct disorders were the most common disorder amongst looked after children (37%), whilst 12% were shown to have emotional disorders (anxiety and depression) with 7% diagnosed as hyperactive. Overall, young people diagnosed with a psychiatric disorder were more



likely to be boys, aged between 11–15, be placed in residential care and to have been in their current placement for less than three years. Even when compared to children in a community sample from the most deprived socio-economic groups, looked after children still showed significantly higher rates of mental health disorders.

Longitudinal studies of adopted children are likely to have a higher IQ, better educational attainments and better family relationships than children from similar backgrounds who remain with biological parents or are fostered (e.g. Andresen, 1992). None the less, a significant minority of adopted children will manifest a range of emotional and behavioural difficulties in adolescence of varying severity (e.g. Fergusson, Lynskey & Horwood, 1995). There is also evidence that adopted children are overrepresented in child psychiatric clinical populations (Warren, 1992). Children adopted at older ages (which can range from 6 months to early adolescence) generally experience adverse care experiences prior to their placement. These children appear more likely to exhibit a number of psychosocial problems than those adopted as babies (Fratter, Rowe, Sapsford & Thoburn, 1991).

In foster care and adoption, many of the children come into care due to conditions of emotional or physical abuse and/or neglect. Children from adoption or in foster care may experience emotional, behavioural and learning difficulties, and are at higher risk for neurodevelopmental problems. Unknown factors in many cases, such as pregnancy risk, alcohol/drug misuse during pregnancy, prematurity, health care deficit, and most of the cases, institutionalisation, can have an effect on children's brain development and psychosocial adaptation (for extensive reviews see Rutter, 1981, 1982, 1984). In addition, entering the care system is usually a traumatic experience for the child, which affects their own sense of security, confidence and self-esteem. The adoptive and foster care family characteristics have been associated with negative developmental consequences that place children at risk for behavioural, psychological, developmental, and academic problems (Curtis, Dale, Kendall, & Rockefeller, 1999). In addition, the child encounters new challenges, such as reshaping secure attachment relationships. The early cognitive and emotional experience of the child is now known

to have a physical impact on how the brain develops (Dent, 2006). The work of neurodevelopmental researchers has increased understanding of the impact of poor early experience on the child's developing capacity to regulate emotion and to develop reflective function (for example Fonagy, Gergely & Jurist, 2002). These capacities in turn influence the child's ability to benefit from experience and so their broader development.

### **1.3 The CAFT service**

The Conduct, Adoption and Fostering Team (CAFT), is a nationwide highly specialised child and adolescent mental health service. It is the result of the union of two independent teams in the past: the Conduct problems team, and the Adoption and Foster Care team.

The Adoption and Foster Care team provides a service for children 0 to 18 adopted or in foster care who are experiencing difficulties. These may relate to their emotional or behavioural development or to more specific placement issues, including failed placements, the degree of contact with siblings or birth family and permanency planning. The team aims to strengthen secure attachment relationships between children and their adoptive or foster family by working together. One of the parts of the intervention is the parenting work with the families, following the evidence-based recommendations in order to overcome the emotional and behavioural difficulties and contribute to the quality of the attachment relationship. The interventions provided are grounded on an intensive multidisciplinary assessment of the child and the family. In this assessment clinical psychologists, psychiatrists and specialised clinicians are involved. From the initial assessment, treatments are tailored to the child and the family needs.

#### **Interventions**

Interventions in the clinic range from individual cognitive-behavioural therapy, cognitive life-story work, systemic work with the family, medication initiation and monitoring and highlighting the work on improving the parent and child relationship using real-time coaching; the "Parent-Child Game." Treatments are evidence-based:

the combination of clinical practice experience and the research information.

#### **1.4 Background and rationale for piloting a social skills group**

##### **Government and NICE guidelines**

Over the past five years the Department of Health and the Youth Justice Board have supported a range of pilots of intensive interventions for looked after children and children on the edge of care or custody. The Adoption and Children Act (2002) places a duty on local authorities to maintain an appropriate service for adoption support. The adoption support services regulations require local authorities to conduct assessments of adoption support needs when requested by an adoptive child, their parents, natural parents or former guardians. The government proposes to reduce the delays in the adoption process and make improvements to the recruitment, preparation and assessment of prospective adopters.

Adopted and Looked after children may have a range of complex and challenging behaviours which can result in out of home placements or placement breakdown. In 2011 the Department for Education (DFE) published a policy for improving the adoption system and services for looked after children (DFE, 2011). The DFE produced a prospectus for 'delivering intensive interventions for looked after children and those on the edge of care or custody and their families' (DFE, 2011). The prospectus aimed to support local authorities and partner agencies in moving towards delivery of specialist evidence-based interventions for supporting looked after children and children on the edge of care as a group. The Department of Health and the Youth Justice Board outlined a number of interventions that were eligible for funding, which included pilot programs that demonstrate efficacy in:

- Improving school success and pro-social skills;
- Improving parenting skills and reducing stress levels in parents, carers and foster carers reducing behaviour problems including diagnosable conduct disorders;

- Reducing antisocial behaviour, substance misuse and association with antisocial peers;
- Reducing re-offending and re-conviction rates for young offenders and reducing time spent in custody.

The prospectus highlights that further work is needed to provide evidence based interventions aimed at improving outcomes for children in care and their families.

NICE guidelines (National Institute for Clinical Excellence) recommend evidence-based programs aimed at improving parenting skills as the effective part in the treatment of behavioural difficulties, and thus contributing to the improvement of the parent-child relationships (NICE, 2010).

### **Parenting interventions**

Children's welfare depends largely on the high quality of parenting, and evidence highlights that interventions with parents, such as the "Parent-Child Game", help to strengthen family relationships and the development of a secure attachment. The "Parent-Child Game" is routinely delivered by CAFT to families referred to the adoption and fostering service and is designed to be performed in eight sessions of one hour weekly. Parenting training consists of working with parents and children at the same time. The therapists observe the interaction through a one-way mirror and make suggestions to the parent through an ear-bug from the theoretical framework explained before and after the clinical experience.

Despite the clear efficacy of parent training, this approach does have some shortcomings: First, although parent training results in predictable improvements in child behaviour at home, it does not necessarily result in improvements at school (Taylor & Biglan, 1998). Second, some parents of children with emotional and behavioural problems cannot, or will not, participate in parent training (e.g. because of work conflicts and life stress). Third, some parents have difficulty implementing or maintaining the strategies taught in parent training due to their own interpersonal and family issues (Webster-Stratton, 1990b). These limitations of parent training have led

to a second treatment approach; that is, directly training children in social skills, problem solving, and anger management (e.g. Shure, 1994). The theory underlying this approach is the body of research indicating that children with emotional and behavioural problems show cognitive and behavioural deficits with peers (e.g. Coie & Dodge, 1998). Webster-Stratton & Lindsay (1999) found that referred children showed more negative attributions, less ability to problem solve, and fewer social skills during play interactions with friends than a matched comparison group of typically developing children

### **Adopted Children and Looked After Children social skills problems**

The literature addressing looked after children's social behaviour is relatively sparse, but some conclusions regarding looked after children's social behaviour can be made. Both parent and teacher reports suggest that looked after children have higher rates of peer difficulties than non-adopted parent-reared children (e.g. Gunnar & van Dulmen, 2007). Indiscriminate friendliness, which is often thought to relate to attachment problems (Rutter et al., 2001) and difficulty understanding social cues and social boundaries may be observed in looked after children (e.g. Fernyhough, Audet & Le Mare 2002). Further, indiscriminate friendliness tends to relate to behaviour problems, such as attention problems, hyperactivity, and disruptive behaviour (e.g. Le Mare & Audet, 2002), and might be related to deficits in inhibitory control more than to attachment (Bruce, Tarullo, & Gunnar, 2009). Autistic-like features have been reported in post-institutionalised children, but these characteristics are thought to have a different aetiology than autism itself (Rutter et al., 1999). Specifically, Rutter et al. (1999) found that compared to children adopted domestically before 6 months of age, 1990s Romanian post-institutionalised children had more repetitive stereotyped behaviour as well as poor social skills characterised by poor reciprocity, poor appreciation of social cues, and a lack of normal social boundaries.

In the case of placing older children for adoption, there has been a research emphasis on rates of breakdown and disruption rather than on developmental and behavioural outcome. Breakdowns are cases in which adopted children either left or were removed

from their adoptive family and to all intents and purposes the adoption was terminated (Barth & Berry, 1988). In the case of placing older children, breakdown rates have been found to vary between 10% and 50%, the rate of breakdown increasing with the rise in age of the child at the time of placement (Borland, O'Hara, & Trisehotis, 1991). The main problems experienced by older placed adopted children include social relationship difficulties with peers and lower likelihood of having a special friend (Rushton, Treseder, & Quinton, 1995).

The CAFT team found that referred children show similar patterns of social and communication deficits as described in the research; including high rates of peer difficulties and poor social skills for example. These difficulties are not shared by all of the adopted children that are referred to CAFT, but they are more common. Although specialist neuropsychological and social communication assessments are in place, current psychological treatment options do not specifically target social skill problems.

### **Social skills interventions**

Given, the commonality of social skills deficits in adopted and looked after children discussed above; there is a need to explore the use of social skills interventions among this group of children. However, evaluation of social skills and cognitive interventions for adopted and looked after children are limited. To our knowledge there has been no published report of any social skills intervention studies conducted with this population. Much of the literature on social skills training for children has focused on interventions with younger children on the autistic spectrum (Wolfberg & Schuler 1993). Few social skills interventions have been devoted to investigating the efficacy of social skills training for young people that are less socially impaired, such as young people with Asperger's Disorder or high functioning autism (Marriage et al. 1995).

Ozonoff and Miller (1995) taught 5 high functioning adolescents with ASD basic interactional and conversational skills and how to infer the mental states of others (Theory of Mind) over 14 sessions. Comparison with 4 non-treated controls demonstrated significant improvement in false belief tasks in the treatment group only, but parent and teacher ratings of social competence, as measured by the Social

Skills Rating System (SSRS) (Gresham & Elliott, 1990), did not improve. Moreover, the authors reported negative correlations between Theory of Mind scores and parent and teacher ratings on the SSRS. In a separate study, Tse, Strulovitch, Tagalakis, Meng & Fombonne (2007) conducted social skills treatment for 13–18 year olds in 12 weekly outpatient group sessions. Intervention content was adapted from Goldstein and McGinnis (2000) and was presented through didactic instruction of new skills and role plays. Although there was no control group, parent report measures showed gains in social competence and decreases in problem behaviours following the intervention. Changes in friendships were not measured.

Several promising classroom-wide interpersonal social skills training programs have shown small, short-term reductions in conduct problems, but long-term results are less clear (e.g. Grossman et al., 1997).

Controlled trial evaluations with children with conduct problems have demonstrated that treatment focusing on social skills, problem solving, and anger management strategies effectively reduces conduct problems (Kazdin, Siegel, & Bass, 1992) and promotes positive peer interactions (Webster-Stratton & Hammond, 1997), particularly if used as an adjunct to parent training. However, the generalisation to other settings and sustainability of child training is unclear. Further efforts are needed to develop and evaluate comprehensive, developmentally appropriate child training treatment programs to foster generalisation of skills across settings.

Webster Stratton et al. (1991), Dinosaur Child Social Skills and Problem Solving training program was successful in producing statistically and clinically significant improvements in child conduct problems (i.e., aggressive behaviours) and in children's cognitive social problem solving strategies at post treatment. Parent and teacher reports and independent observations indicated that these changes were produced both at home and in the classroom, suggesting that the program resulted in behaviour change that generalised across settings. The follow-up assessments indicated that most of the clinically significant improvements were sustained over time. However, at l

year follow up we no longer had an untreated control group.

These findings suggest that social skills and problem solving training is a potentially useful treatment alternative for children with conduct problems. To our knowledge, there has been no published report of a social skills group intervention for adopted children or looked after children and children on the edge of care or custody.

### **1.5 Project Aims**

This project was developed in line with government policies with the intention to continue to develop evidence based interventions for adopted children, looked after children and children on the edge of care or custody. Specifically, this project was developed within the Department for Education recommendations for interventions that demonstrate effectiveness in improving pro-social skills and reduce antisocial behaviour and association with antisocial peers for looked after children and children on the edge of care or custody (DFE, 2011). This project aims to deliver a pilot intervention for adopted and looked after children who show subtle social skills deficits (e.g. difficulties sustaining friendships/perspective taking) rather than frank social communication difficulties seen in the autism spectrum disorders and evaluate its efficacy.

Specific objectives include:

- 1) To assess the feasibility of recruitment, retention, and satisfaction with a newly developed social skills intervention group for adopted and looked after children who show subtle social communication difficulties.
- 2) To assess the feasibility of collecting measures from young people, parents and teachers.



## 2 Method

### 2.1 Developing a social skills group in CAFT

The 7 week social skills training course named 'SCENE' took place at the Michael Rutter Centre. The full 7 week protocol can be seen in Table 1. This protocol was based primarily on the manualised PEERS intervention program (Laugeson & Frankel, 2010) which was developed for young people from 13-17 years with a diagnosis of Autistic Spectrum Disorder (ASD). The authors recommend that this program is suitable for young people with a wide range of emotional or behavioural difficulties and they provide data for its efficacy for children with conduct disorder and Attention Deficit Hyperactivity Disorder (ADHD). Although no data has been published for its efficacy for adopted and looked after children who show subtle social skills deficits, the skills areas to be targeted are similar to those young people with a diagnosis of ASD. Therefore, it was decided that this intervention would be appropriate for these young people. In addition, as yet there are no evidence based individual or group intervention programs that have been developed for the needs of this specific client group. Therefore, this program was chosen to assess its feasibility for young people who did not have a diagnosis of ASD but present with social and communication difficulties. However, the program was tailored to fit the specific needs of these young people and therefore not all areas of the PEERS program were covered.

Based on the intervention developed by Frankel and Myatt (2003), SCENE addressed current social functioning among young people in five areas. The areas chosen were decided in consultation with the CAFT team to be specific for the needs of these young people, which included: (a) reciprocity in conversations in order to develop meaningful friendships; (b) diminishing the importance of the rejecting peer group for the young person by promoting skills to expand the young person's social network (c) abating the effects of the young person's negative reputation within the current peer group through instruction in the rules of peer etiquette; (d) avoiding continuing provocation from peers by improving the young person's competence at handling teasing, bullying, and other conflicts with peers.

SCENE consisted of 90-min sessions, delivered once a week over the course of seven weeks after school hours. Sessions were structured such that each session began with a review of the homework assignment from the previous week (see table 1 for a description of the individual session contents). In order to individualise the program to suit the specific needs of each young person, sufficient time was allotted to troubleshoot any homework problems. This portion of the session was followed by a didactic lesson, which was outlined in a handout for the young person and parents. The Parent handouts included a summary of the skills taught in the session. Young person's didactic lessons were followed by demonstrations in which the group leaders modelled the appropriate social skill being taught and through role-play exercises. Newly learned skills were rehearsed by the young people in the session, during which they received performance feedback from the group facilitator and co facilitator. Homework was then assigned for the coming week, allowing time to troubleshoot potential barriers to homework completion.

**Table 1: Description of sessions**

Session Number	Didactic lesson	Description of the lesson	Homework
1	What makes a good friend and trading information	Trading information during conversations with peers in order to find common interests. Having two-way conversations with peers.	Young people practice trading information with non-group member.
2	Electronic communication	Appropriate use of voicemail, email, text messaging, instant messaging, and the Internet in developing pre-existing friendships.	Young people practice using electronic forms of communication
3	How to make appropriate friends and rules about humour	Young people taught the social structure of school peer groups and identify groups they might fit in with.	Young people identify a potential peer group
4	Tease the tease and handling embarrassing feedback	Appropriate responses to teasing. Differentiating between teasing and negative feedback and using appropriate responses to the latter	Young people practice handling teasing appropriately
5	Changing bad reputation and good sportsmanship	Strategies for handling bullying and changing a bad reputation. The rules of good sportsmanship during games and sports	Young people practice good sportsmanship. Young people use new strategies for handling bullying and begin to change bad reputations
6	Handling disagreements	Resolving disagreements with peers	Young people practice handling arguments with friends
7	Party	Games and prizes for young people	

## 3 Design

### 3.1 Participants

#### Recruitment and Eligibility

Young people (aged 12-15) were recruited from the Adoption and Fostering team (National & Specialist CAMHS service) situated in the Michael Rutter Centre (MRC), Maudsley Hospital. All participants were registered patients under the care of the Conduct and Fostering team.

Inclusion criteria for young people were: (a) chronological age was between 12 and 15 years; (b) social problems as reported by the parent or young person;

Exclusion criteria for young people were: Young people that presented with (a) a verbal IQ of 70 or below (b) history of major mental illness, such as bipolar disorder, schizophrenia, or psychosis; and (c) hearing, visual, or physical impairments which precluded young person from participating in outdoor sports activities.

When considered appropriate for inclusion in the group invitation letters were sent to potential participants (Appendix 1). This research and the associated documents had received ethical approval from the South West London REC 3 NHS National Research Ethic Committee.

### 3.2 Measures

#### Quantitative

Test of Adolescent Social Skills Knowledge (TASSK; Laugeson and Frankel 2006)

The TASSK is a 22-item criterion-referenced test developed for this study to assess the young person's knowledge about the specific social skills taught during the intervention. Two items were derived from key elements of each of the 11 didactic lessons. Participants were presented with sentence stems and asked to choose the best option from two possible answers. Scores range from 0 to 22, with higher scores reflecting greater knowledge of young person social skills. Coefficient alpha for the TASSK was 0.56. This moderate level of internal consistency was acceptable, given the

large domain of questions on the scale.

#### Social Skills Rating Scale (SSRS; Gresham & Elliott 1990)

The SSRS was sent to teachers and parents at the beginning and end of the group. The questionnaires consist of 38-items and took approximately 10 min to complete. Questionnaires include parent and teacher forms. For example, items included “Starts conversations rather than waiting for someone to talk first.” The items are rated as either “Never,” “Sometimes,” or “Very Often.” The Social Skills and Problem Behaviours scales were derived from factor analysis. Gresham and Elliott (1990) reported the psychometric properties of the parent and teacher forms for young people. Social Skills scale coefficient alphas were 0.93 for teacher and 0.90 for parent forms and for the Problems Behaviour scale they were 0.86 and 0.81, respectively. Correlations between teacher and parent forms were low (Social Skills and Problem Behaviour scales  $r$ 's = 0.36) but statistically significant ( $p$ 's = 0.0001). Both scales were transformed into standard scores with a mean of 100 and standard deviation of 15. Higher scores on the Social Skills scale indicated better social functioning and lower scores on the Problem Behaviour scale indicated better behavioural functioning.

#### Quantitative measures of acceptability (weekly feedback questionnaire)

A feedback questionnaire was given to young people after each session asking them to evaluate their enjoyment, relevance and duration acceptability for each session on a likert scale 0-100 (see Appendix 2 questions 1-3 for an example of a weekly feedback questionnaire).

### **Qualitative**

#### Weekly feedback questionnaire

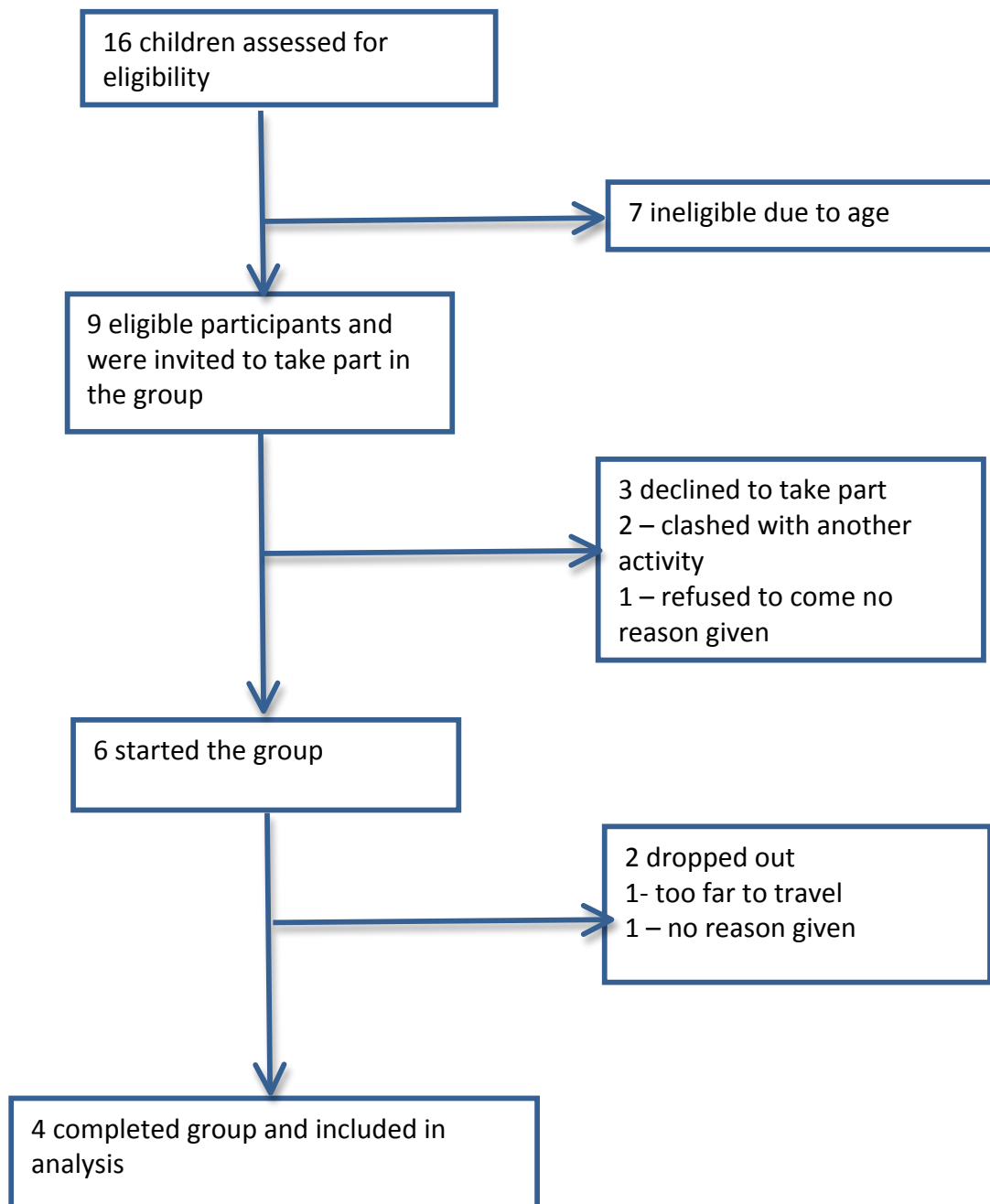
The evaluation was structured using a range of methods to create genuine user involvement. Firstly an opportunity was created for weekly feedback asking the young person's questions such as, ‘what was most and least useful?’ (See Appendix 2 question's 4-8 for an example of a weekly feedback questionnaire) Secondly, evaluation involved a semi-structured interview with young people, which included

questions to group members to draw out their experiences of the group. Questions were focused on perceived benefits of the intervention, useful aspects of the group, ideas for adaptations for future groups and identification of anything that they had found unhelpful.

## 4 Results

### 4.1 Patient recruitment

Sixteen young people known to the Adoption and Fostering team were assessed for eligibility. Seven of these were ineligible due to their age. Nine young people met inclusion criteria at the time of recruitment and were contacted to be invited to the group. Of the 9 eligible participants, 3 people declined to take part. The reasons for declining to take part, obtained from all 3 participants, were: clashed with another activity (n= 2) and refused to come to the MRC (n=1). 6 participants took part in the pilot study. 2 participants dropped out. The reason for dropping out, obtained for one participant, was: too far to travel to the MRC. 4 young people that completed the intervention all attended at least 75% of sessions (minimum of 5/7). See Figure 1 for a CONSORT diagram of recruitment. Two girls, both 13 years old, and two boys, both 14 years old, completed the pilot study.



**Figure 1: CONSORT diagram**



## 4.2 Quantitative Results

### Satisfaction ratings

Satisfaction ratings from the weekly feedback questionnaire provided by the four participants who completed the course can be seen in Figure 2 and Figure 3. All participants gave ratings of between 70 (very much) and 100 (extremely) on measures of enjoyment of the session and of whether the topics were relevant to them for each session. Overall mean enjoyment ratings were scored at 86% and mean relevance ratings were scored at 83% across all the sessions (see Appendix 4 for raw scores). Lower ratings were provided by participants on measures of duration (whether there was enough time given to cover the topics in the session). Overall mean duration ratings were scored at 73%. All participants explained that they would have liked sessions to be longer when they were asked for feedback at the end of the group. See Appendix 4 for the raw data. Weekly feedback questionnaires were given to participants at each SCENE session and time was allocated for participants to complete these forms and hand them back before the end of the session.

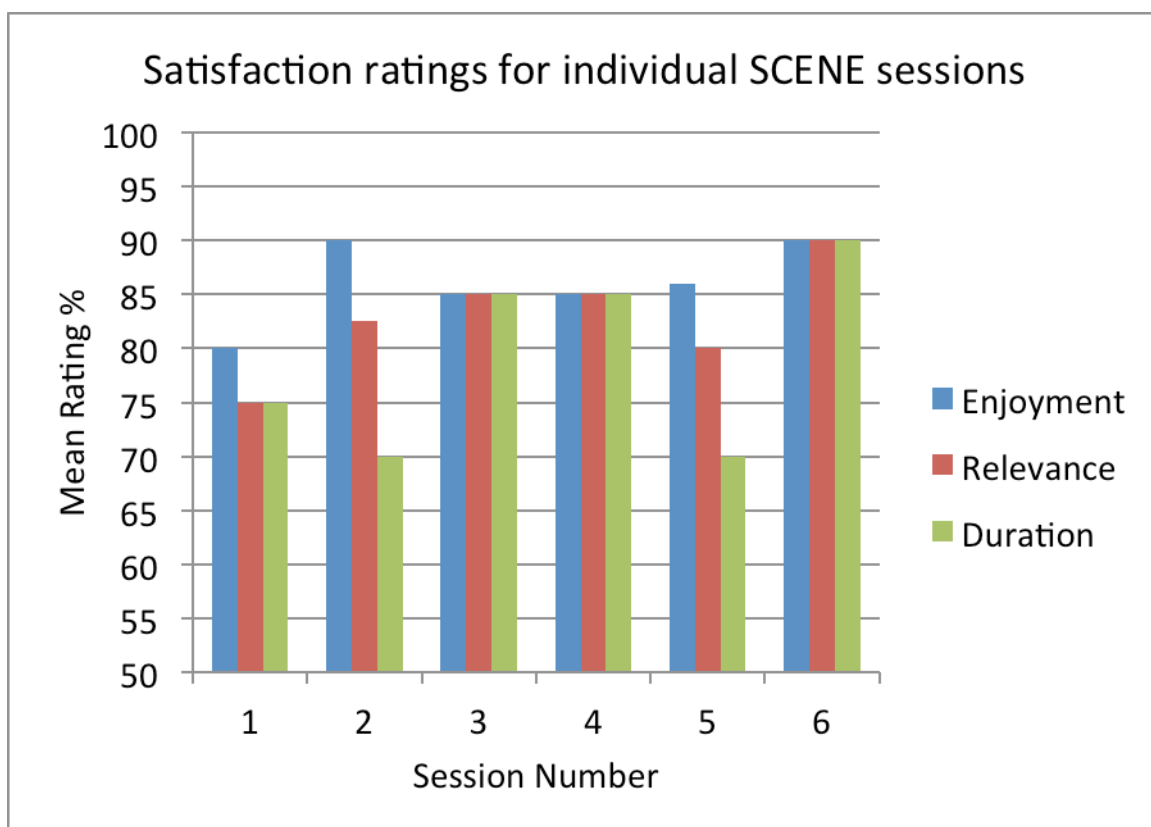


Figure 2: Satisfaction ratings for individual SCENE session

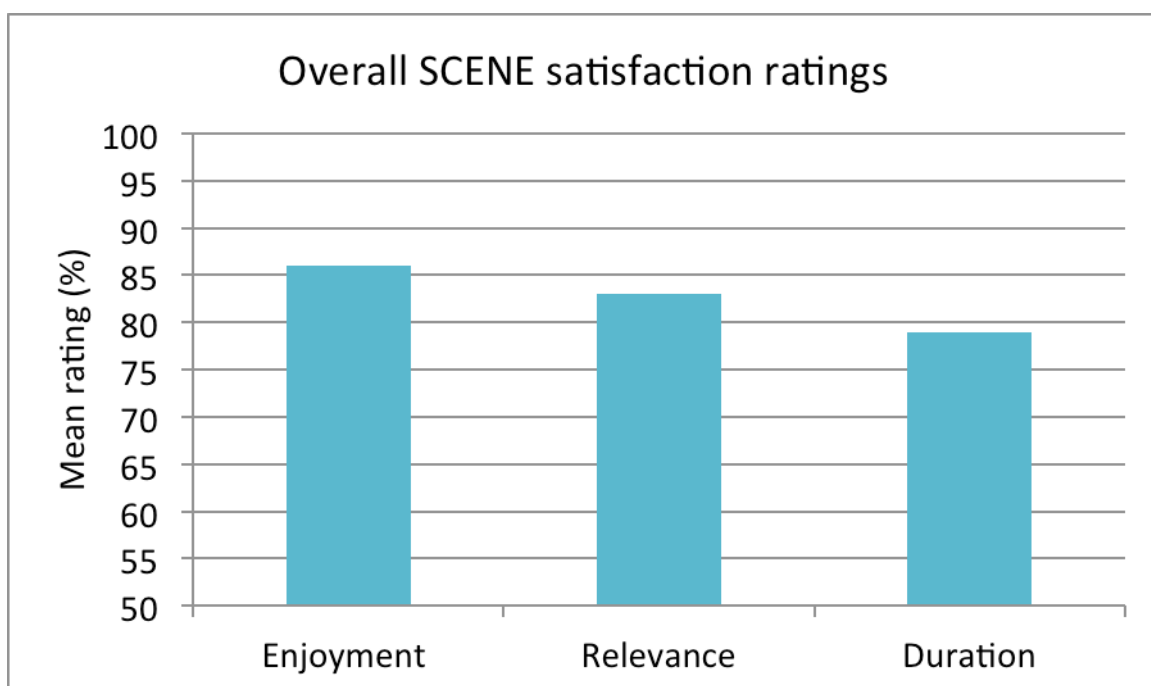


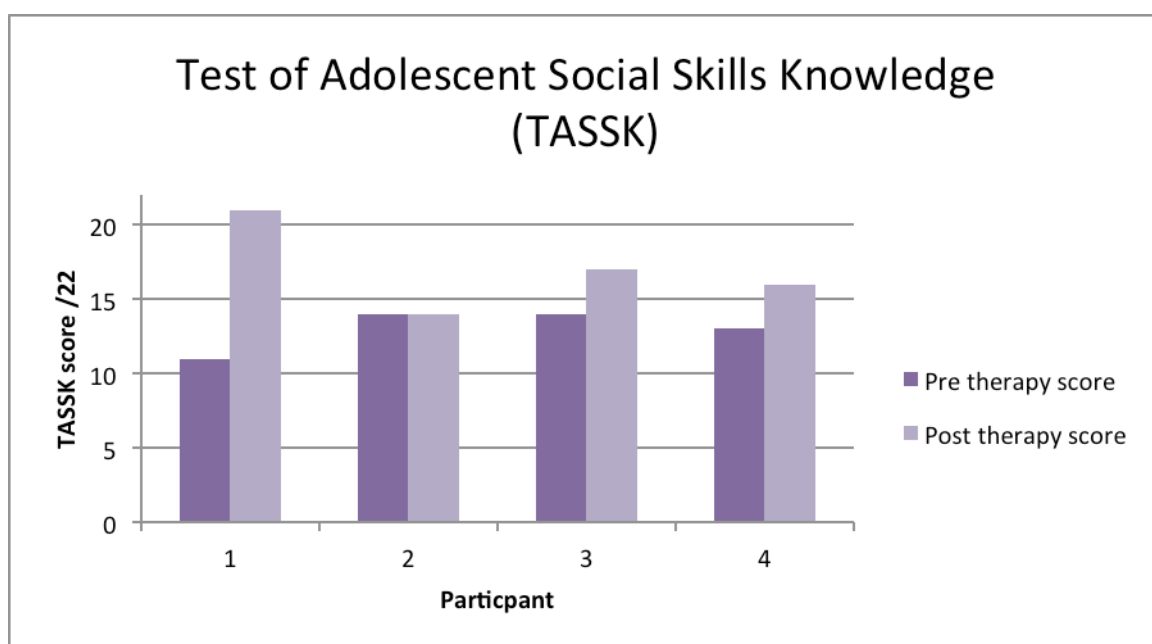
Figure 3: Overall SCENE satisfaction ratings

Social Skills Rating Scale (SSRS; Gresham & Elliott 1990) teacher and parent forms

All teacher and parent SSRS measures were sent by post to parents and teachers before the group. Stamped addressed envelopes were enclosed for parents and teachers to return the measures via post to the MRC. Participants were reminded at the beginning of the first 3 SCENE sessions to bring the parent forms with them to the following session. No further follow up for teacher forms were made. Out of all the measures sent out only one pre-group teacher form and one pre-group parent teacher form were completed for a participant whom then dropped out of SCENE.

Test of Adolescent Social Skills Knowledge (TASSK; Laugeson & Frankel 2006)

The TASSK measure was administered to participants at the start and end of treatment (see Appendix 4 for raw scores). Time was given during SCENE session 1 and 6 for participants to complete these measures and hand them back to the facilitators. Figure 4 shows participants' social skills knowledge, measured by the TASSK before and after the intervention. Three participants showed an increase of their social skills knowledge during the course of the intervention and although one participant's scores did not change, overall the group showed a significant increase in their knowledge of social skills (see table 2).



**Figure 4: TASSK outcome measures**

**Table 2: Mean TASSK scores before and after intervention**

TASSK		
Mean Pre therapy score	Mean Post therapy score	significance
13 (SD=1.41)	17 (SD = 2.94)	P=0.02

### 4.3 Qualitative feedback

The evaluation was structured using a range of methods to create genuine user involvement. Firstly an opportunity was created for weekly feedback asking the young person's questions such as, 'what was most and least useful?' 'Did anything wind you up in today's session?' (See appendix 2 for example of weekly feedback questionnaire) Secondly, evaluation involved a semi-structured group interview with participants, which included questions to group members to draw out their experiences of the group. Questions were focused on perceived benefits of the intervention, useful aspects of the group, ideas for adaptations for future groups and identification of anything that they had found unhelpful.

Data from the weekly feedback form and the semi structured interview was analysed for themes emerging within individual questions and subsequent discussion. Particular attention was paid to areas of consensus between participants and to topics pertinent to service development. Four themes emerged, which will be described in turn below. These were: beliefs about the benefits of SCENE; thoughts about the methods used in the group; responses to being in a group and the logistical arrangements of the group.

#### **Beliefs about the benefits of the group**

All participants expressed beliefs about SCENE helping them to learn and use new skills:

*"I learnt about handling arguments and disagreements, how to say sorry and listen to other people."*

*"I learnt how to protect yourself against bullying like to tease the tease. If it is physical bullying then tell the teachers and lay low and like don't do anything that may upset them...or provoke them."*

*"I found learning about bullying the most helpful thing because I get beaten up quite a lot...like to learn how to avoid them."*

*"Making friends and not all about getting someone to like you about finding things in common liking each other."*

*"Learning how to deal with problems in a cool calm way."*

*"How to listen for longer and how to start and keep conversations going."*

*"How to trade information and help stop you being bullied."*

*"Learning how to say things like 'good job', 'well done' and being a good sport.'*

There was a consensus between participants that they would recommend SCENE to other young people with similar difficulties.

In summary, the comments made by participants in relationship to the perceived benefits of SCENE and the skills they have learnt indicate that they were able to accept a group social skills training course to address subtle social skill deficits among looked after children.

### **Methods of teaching**

Participants were asked which teaching methods they found most helpful. Two themes of methods of teaching emerged from the interviews. These were methods related to role playing and didactic methods.

One participant described the benefits of role playing:

*"The role-playing - it was like practical and it was actually like useful like a play or rehearse of what would actually happen if you are disagreeing with being bullied or whatever it's like good practice."*

Another participant described didactic methods of teaching as being more helpful:

*"Reading and listening to you two, I think I was really helpful because that is where you get most of the information from."*

### **Being in a group**

Participants were all positive about being in the group:

*“Meeting new people are all really really nice.”*

*“Talking to the others about it (the teasing)”*

*“Helping other SCENE mates to overcome teasing.”*

Participants were asked each week if they would have liked anything to be done differently and whether anything ‘annoy you or wind you up in today’s session?’ In addition, participants were asked in the group interview whether they could suggest anything that could be improved or done differently for SCENE groups in the future. No comments were provided for potential improvements. However, two participants expressed their perceived enjoyment of the group and desire for further sessions or revision sessions:

*“The whole thing, it was really brilliant...I wish it lasted longer.”*

*“We do not necessarily have to say like this is the last time cause I was thinking could you do like revision sessions?”*

## 5 Discussion

### 5.1 Feasibility and satisfaction of SCENE

Both quantitative and qualitative measures of satisfaction indicate that SCENE was satisfactory to this small group of young people. Participants who completed the intervention were both willing and able to attend. Participants were positive about the premise of SCENE, the content and format of the group sessions and the structure of the intervention. They valued the topics covered and the methods of teaching used. Although in the feedback interviews each participant expressed positive views about SCENE, they also indicated a desire to have longer sessions.

The extent to which we are able to comment on the efficacy of SCENE for this group is limited by the small number of participants, and even smaller number of completers. However, we can tentatively conclude that all completers responded to the intervention, as evidenced by improved knowledge of social skills as measured by the TASSK. Although these results are encouraging, the low number of participants, the absence of a control group and follow up data means that the results can be used merely to provide justification for future piloting rather than clear evidence that SCENE is efficacious with this group.

The withdrawal and refusal of a third of participants to attend the intervention and in addition, the poor response rate from teacher and parent measures is indicative of the importance of thorough piloting and assessment for suitability before commencing this intervention.

Although preliminary, both outcome and satisfaction measures provide encouraging results, as participants demonstrated improved knowledge of rules of social etiquette relevant to making and keeping friends. However the power of this study was adversely affected by the low number of completing participants and therefore no meaningful conclusions can be made about the efficacy of SCENE. One way to overcome the difficulty of identifying sufficient numbers of young people ready for the intervention at the same time might be to use a 'rolling' group. Another possibility might be to involve previous participants in the recruitment of future young people.

For example, the Coping Cat program (Kendall, 2006) (a cognitive-behavioural therapy intervention for anxious children) encourage previous participants to make a short video about their experiences of the group and then show it to subsequent children. This approach has been shown to be an effective method to increase participation and it is possible that this method may help to increase number of participants for future piloting of SCENE interventions.

It is likely that some of the reasons that young people may have declined the group may have been related to their presenting difficulties. For example perhaps young people with social skills problems find the prospect of a group setting rather threatening or anxiety provoking. It is important to thoroughly assess each individual so that the recruitment method can be individually tailored to the young person's needs and difficulties.

Future research should aim to develop our ability to assess the suitability of young people for a course of SCENE, perhaps by carrying out an intake interview providing an opportunity for the young person to gain a clear understanding about the group before enrolling. Research should also aim to examine other informant's reports, such as parents and teachers assessment of participant's outcomes, to provide a less biased outcome.

## **5.2 Feasibility of collecting measures for SCENE**

Perhaps the most significant implication for service development are the challenges in retaining adopted and fostered young people in a social skills group and the feasibility of collecting postal measures from parents and teachers. These findings highlight the importance of further piloting of SCENE.

The weekly feedback questionnaires were given to participants at each SCENE session and time was allocated for participants to complete these forms and hand them back before the end of the session. The TASSK measures were administered to participants at the start and end of treatment. Time was given during SCENE session 1 and 6 for participants to complete these measures and hand them back to the facilitators. The



facilitators were careful to check that each item on both questionnaires was completed before collecting the measures. The 100% completion rate of both the TASSK and weekly feedback questionnaires provide provisional indications for the suitability and user-friendliness of these measures of social skill knowledge and SCENE satisfaction. The method of administration provides preliminary support for the success of collecting measures face-to-face during SCENE sessions, due to the high completion rate. These results highlight the importance of administering measures face-to-face, allocating specific time within the session to ensure completion and return of the measure. Future piloting is needed to administer the TASSK and weekly feedback questionnaires in this same way to provide further evidence for the efficacy of these measures and method of administration. In addition, further piloting could also assess the feasibility of administering the parent measures face-to-face. For example, parent measures could administered to parents either during an 'intake interview' with their child (see section 5.1) or at the beginning of the first SCENE session. Efforts should be made to ensure that each item on the measures are completed before collecting the parent and participant forms.

Several reviews and meta-analyses of strategies to increase response to postal questionnaires have been published in the literature on research surveys over the past 40 years (Edwards, 2001). Edwards (2001) carried out a systematic review of randomised trials of any method to influence response to postal questionnaires and identified a range of strategies that seem to increase response to postal questionnaires: short questionnaires made response more likely; the use of coloured ink as opposed to blue or black ink increased response as did making questionnaires and letters more personal. Contacting participants before sending questionnaires increased response as did follow up contact and providing non-respondents with a second copy of the questionnaire (Edwards, 2001). The provision of financial or material 'incentives' is also an important strategy used to increase retention in studies with vulnerable populations. Kotch (2000) states that research participation 'is partially motivated by altruism' but it is assisted by the provision of 'a modest financial compensation' and the promise of confidentiality. Future piloting could benefit from

applying these strategies to administering and collecting parent and teacher forms that have been shown to be effective from this systematic review. Although it may be possible to administer parent forms face-face, collecting measures from teachers has clear implications for resources. Therefore, further piloting may initially want to assess the feasibility of applying strategies to increase response to postal questionnaires, such as contacting named teachers before sending questionnaires and providing follow up contact or sending online questionnaires, for example.

### **5.3 Implications for service development**

The findings of this study have been shared with the CAFT team. The results and implications for service developments from the project have been disseminated at the weekly team meeting. Copies of all of the SCENE related materials, such as presentation slides, session contents and blank outcome measures have been provided for the team for future piloting. This has led to initial discussions about the development of collaboration between CAMHS National and Specialist Services to enhance the provision of SCENE in N&S services. The facility to run further SCENE groups with greater numbers of participants may be of benefit in improving service users' experience of a group environment, increasing the power for research studies and being economically more efficient as greater numbers of young people are treated concurrently. The CAFT service is currently in the initial stages of developing these ideas in team meeting discussions.

The work also raises a number of points for consideration by the service when running future groups. These include the duration of sessions, teaching methods used in the group and revision sessions after the group. First, participants were enthusiastic about the contents of the protocol and the range of activities. However, it may be worth further considering longer sessions or reducing the contents to be covered. The participants here found SCENE sessions relevant and enjoyable, however lower scores of satisfaction were given for the duration of sessions. Participants explained in the feedback interview that they would have liked sessions to be longer. Each of the six sessions lasted 90 minutes, with a 10-15 minute break. One way of overcoming the difficulty of duration may be to provide 2 hour sessions in future. Initially, SCENE was

intended to run for eight sessions, however due to difficulties with recruitment and trainees placement finishing, it was reduced to six. Alternatively, increasing the number of sessions to eight or ten may be worthwhile exploring.

Another issue linked to the size of groups is the difficulty for breakaway discussions and role plays to be practiced with other young people. Role plays were highlighted by participants as being a preferred method of teaching. However, facilitators were often required to be involved in the role plays. Although participants did not discuss any difficulties with the size of the group a larger group number would allow for participants to practice different social skills taught with a variety of different young people and thus enable more generalisability. A larger group may have also been beneficial for participants to further validate the shared experience of other young people experiencing similar difficulties.

Participants shared a desire to have revision sessions beyond the end of the group. It may be beneficial to consider ways in which the service would be able to support follow up groups or regular practice sessions being offered to young people who have completed SCENE. This has clear implications for resources, but may facilitate the continued benefits of social skills improvements, which in itself would be beneficial. One option which might allow for group completers to return for booster or follow up sessions, and which was discussed earlier would be to use rolling group membership. This may also allow for participants to continue developing their social skills.

#### **5.4 Limitations**

Many of the limitations of this work have been alluded to above. The first and most finding is the extremely low number of young people recruited into and completing the intervention. As such result presented here, whilst encouraging, can only be seen as preliminary.

Second, non-completers were not followed up for either satisfaction ratings or for qualitative feedback. This limits our findings to those that did find the intervention acceptable and so does not allow us to comment on what changes may have held the others in the group.

Third, parent and teacher outcomes were not reported. More attention should be paid to capturing other informant's view, since they are not directly involved in treatment and can provide a less biased view. In future it may be worthwhile asking parents to attend the first and last sessions of SCENE and to administer the questionnaires whilst they are present. Strategies to increase response to postal questionnaires, such as contacting named teachers before sending questionnaires and providing follow up contact need to be applied and assessed. Also, the durability of outcome was not measured after treatment ended.

Finally, the interview was conducted by the clinical psychologist in training, who had been the lead facilitator during the intervention. The interview was also held with the group as a whole. As such it may have been difficult for participants to provide negative feedback about the group or about SCENE itself.

## 6 Conclusion

The work presented here provides preliminary but encouraging indication that SCENE is satisfactory for this group of looked after and adopted young people (n=4). These conclusions are made with a significant caveat, which is that with this low number of participants, the absence of a control group and no follow up only data. Therefore, these findings, while encouraging, are seen to provide justification for future research rather than clear evidence that SCENE is efficacious with this group. Future piloting is needed on a larger sample size to provide stronger support for the feasibility of collecting measures from young people, parents and teachers. Face-to-face administration of young person measures provides preliminary support for the acceptability of this method and future piloting is required to provide further evidence for the efficacy of collecting young person and parent measures in this way. Strategies to improve collection of teacher report measures and assess outcome after a 3 month follow-up period is also needed. It is hoped that these methodological changes will result in increase collection of parent and teacher measures and follow up data.

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## 8 Appendix

### 8.1 Appendix 1: Letter to potential participants

NATIONAL AND SPECIALIST CAMHS

Michael Rutter Centre for Children and Young People  
De Crespigny Park  
Denmark Hill  
London SE5 8AZ  
**Tel:** 020-3228-2546  
**Fax:** 020-3228 5011

Tuesday 24<sup>th</sup> January 2012

Dear xxxx

We are inviting xxxx to attend SCENE. This is a group for young people aged 11 to 14 who show some difficulties in their social skills. During the course we will be discussing social skills and behaviours that will be practiced within and outside the group through homework. Will we be focusing on different skills used in everyday life, such as co-operation, empathy and problem solving. We hope to involve you throughout the course to explain more about the content. In addition, there will be weekly handouts for both yourself and your Child.

The group will be lead by Polly Crawford (Clinical Psychologist in training) and xxxxxx (Assistant Psychologist) under the supervision of Dr Anouk Houdijk (Clinical Psychologist). It is scheduled to start on the 2<sup>nd</sup> of February from 4 to 5.30pm. It will run for 7 weeks and will be held at the Michael Rutter Centre. Regular attendance and coming on time is necessary to get the full benefit of the group and it is important that your son/daughter will be able to attend at least 5 of the 7 sessions.

If you think that your son/daughter would be interested in attending this group, please contact us to confirm.

Polly Crawford  
Email: [polly.crawford@slam.nhs.uk](mailto:polly.crawford@slam.nhs.uk)  
Phone: xxxxx

Email: xxxxxxxx  
Phone: xxxxx

Yours Sincerely,

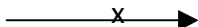
Polly

**Polly Crawford**  
**Clinical Psychologist in training**

**xxxxx**  
**Assistant Psychologist**

## 8.2 Appendix 2

### End of Session feedback Form

Please indicate each answer by marking an 'X' along the line. E.g. 

1. Did you enjoy today's session

\_\_\_\_\_

0 100

Not at all Somewhat Very Much

Extremely

2. Were the topics about friendship and trading information relevant to you?

\_\_\_\_\_

0 100

Not at all Somewhat Very Much

Extremely

3. Was there enough time for friendship and trading information?

\_\_\_\_\_

0 100

Not at all Somewhat Very Much

Extremely

4. Did you learn anything or find out something helpful or useful in today's session?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

5. Did anything annoy you or wind you up in today's session?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

6. What was the best part in today's session?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

7. Is there anything you would like to be different in next week's session?

\_\_\_\_\_

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8. Do you have any other comments?

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### 8.3 Appendix 3: Group Evaluation Semi Structured Interview

#### Overall

One thing you found useful?

Least useful/done differently/changed about group?

What was your best/worst session and why?

#### Teaching Methods

What did you find most useful way of learning e.g. discussion/role play etc?

#### Learning and implementing ideas

Do you think that you have learnt any new skills?

Have you noticed any changes in way you act and feel about making and keeping friends since group?

Have you noticed any benefits in practising skills taught?

Have you noticed any thing you have been doing differently?

Would you recommend scene to other young people?

#### Sharing experiences with other young people – support within group

Can you tell us how you have found being in a group?

Do you prefer individual or group work and why?

#### Group process and dynamics

#### Accessibility – ie practical issues

## 8.4 Appendix 4: Raw data

### Satisfaction ratings

Session number	Content	Enjoyment (mean %)	Relevance (mean %)	Duration (mean %)
1	What makes a good friend and trading information	80	75	75
2	electronic communication	90	82.5	70
3	How to make appropriate friends and rules about humour	85	85	85
4	Tease the tease and handling embarrassing feedback	85	85	85
5	changing bad reputation and good sportsmanship	86	80	70
6	handling disagreements	90	90	90
	Sum of scores	86	83	79

### TASSK scores

Participant number	TASSK	
	Pre	Post
1	11	21
2	14	14
3	14	17
4	13	16